

THE WAR OF WORDS IN THE WAR ON CANCER: CONTEMPORARY  
DISCURSIVE CONTESTATIONS AROUND BREAST,  
BLADDER, AND SKIN CANCERS

by

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## ABSTRACT

Despite decades of awareness and research, cancer continues to grow as a threat to public health. This prevalence indicates the continued importance of attending to how cancer is covered and constructed in public health campaigns (“official” discourses) and mainstream news coverage (“common” discourses), particularly since the latter frequently shapes public perceptions about the disease and the former educates populations about the disease. In this dissertation, I assess and evaluate the differences and similarities between official and common discourses of health, paying particular attention to the existence, location, and mobilization of fissures between these discourses, especially as these fissures could indicate the pervasive discourses around particular cancers that patients are likely to have encountered and that may influence their perceptions of the disease, their experiences, and appropriate treatment. I am guided by four questions: (a) What are the differences, if any, between official and common health discourses of, respectively, breast, bladder, and skin cancers? (b) How are health providers, patients, and specific cancers rhetorically characterized, respectively, within and across official and common discourses? (c) How are individual and structural responsibility (or unaccountability) rhetorically mobilized across these different health conditions? (d) What are the implications of these findings for health information, education, promotion, and intervention efforts?

I answer these questions through a critical rhetorical analysis of two distinct sets

of texts for each cancer type under examination here: official/institutional discourses broadly disseminated to the public about these cancers and mainstream news coverage. Analysis of these texts suggest that, in each case, official discourses characterize cancer, patients, and the medical establishment in ways that are distinct from common discourses. In doing so, this study contributes to extant health communication literature by continuing to parse established knowledge about assumptions of patient responsibility and the role of structural entities in the fight against cancer. This study also complicates the official/common binary in order to apprehend a potential middle ground discourse between official and vernacular discourses, thus resurfacing and redefining the notion of the “common” in order to account for the continued blurring of the line between media producer and consumer.

To Mom—my first and best teacher

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## CHAPTER I

### INTRODUCTION

With the emergence and subsequent privileging of the biomedical approach to health and illness in the U.S. healthcare system, the body has become a normalized site of tensions over which regulatory actions—if any—should be imposed upon it in order to maintain institutional notions of well-being (Lupton, 2012). This approach to health care is contextualized by and situated within a larger political economic system that is heavily informed by neoliberal sensibilities and locates the responsibility for individual health squarely on the patient (Crawford, 1980; Willis, 1991). Thus, how patients understand, discuss, and mobilize issues pertaining to their health is informed by and reflective of these sensibilities and imperatives that are disseminated, in various ways, in public discourses about health.

Although complex and varied, specific understandings of health often emerge from—and are informed by—*official* discourses promoted by the medical establishment to inform patients of optimal health practices and persuade alignment with these practices. Official discourses are generally understood to be those that are widely available and are afforded the cultural authority—by dint, for example, of institutional or structural power—to shape history and how citizens are allowed to exist within spaces constructed by dominant ideologies (Ono & Sloop, 1995). The processes of navigating one's health are further influenced by the lay—or *vernacular*—discourses that circulate

within and represent a specific group's orientation toward the world. Whereas official discourses frequently function as directives that are shaped by and conform to governmental and/or institutional doctrine about health, vernacular discourses arise from the everyday lives and interactions of communities that are operating in material and cultural contexts that frequently are not accounted for in official discourses (Ono & Sloop, 1995). The dramatic rise in participation from and interaction between producers and consumers fostered by dramatic cultural and technological shifts since these concepts were introduced and theorized suggests that the original binary of "official" and "vernacular" may no longer adequately or neatly capture discursive cultural dynamics and contestations over meaning. That is, this emphasis on sharing, responding to, and engaging with mainstream media content in vernacular spaces—for example, blogs and social media posts—challenges the notion that broader public discourses cannot constitute the vernacular because the former and the latter seemingly draw on one another to produce, negotiate, and circulate ideas (Howard, 2008). Howard (2008) puts forward the notion of "common vernacular" discourse in acknowledgment of these shifts in relation to contemporary mainstream media venues. While he finds the concept problematic—effectively hegemonic in its state as a hybrid of vernacular and institutional discourses that confounds attempts to draw clear distinctions between the two—I would like to revisit and explore that concept and assert, essentially, that "common" discourse is more complex and amorphous in its interrelationships with official and, especially, vernacular discourses than Howard (2008) posited (or at least was representative at the time of his writing). Due to dramatic cultural and technological shifts and the widespread take-up of attendant mediated practices and participation on the part of individuals and

communities, mainstream news media in the United States—as privately owned entities—must resonate with highly interactive lay audiences in order to remain popular. As such, mainstream news discourse, I argue, qualifies as a common discourse per the heavy reliance on and responsiveness to audiences given their input into mass mediated articulations that, I assert, is more nuanced and more reflective of cultural imperatives and sensibilities that are—if not more closely aligned with and reflective of vernacular communities than with official discourses—then at least not so far removed from them as Howard (2008) speculated at the time of his writing.

Accordingly, a broader theoretical aim of my project is to explore and assess whether differences in official and common discourses do in fact inhere, thereby justifying at least a conditional expansion of Ono and Sloop’s originary considerations of discourse as informed by a critical rhetorical perspective. In particular, my interest is in assessing intersections and, especially, points of convergence and divergence between conventionally “official” and “common,” mainstream cultural articulations or narratives—discourses—of health. This provides a valuable opportunity to examine how health discourses are generated and proliferated by those who have a vested interest in the processes inherent to receiving and understanding care (i.e., patients) and providing/communicating about care (i.e., health providers). The significant impact of cancer across the United States—resulting in approximately 1.6 million new diagnoses in 2015, with a similar number projected for 2016 (American Cancer Society, 2016b)—provides a key opportunity to examine the potential differences and disparities between official and common health discourses, especially in an historical moment when the validity of knowledge and fact claims are highly contentious. The following proposal

details the necessity of studying cancer-specific discourses—particularly as they pertain to breast, bladder, and skin cancers—in order to identify the points of convergence and divergence between official and what I aver are common discourses on cancer, and to establish the implications of these findings for health promotion, education, and interventions.

### **Communicating Health**

Consistent concerns for health communication scholars since the inception of the discipline have centered on how patients learn about, understand, mobilize, and act on general ideas about health and comply with prescriptive guides from providers (O’Keefe & Jensen, 2007). This emphasis on patient knowledge and understanding frequently extends to how patients talk about their health in both formal encounters with medical professionals and informal engagement in health discourses with family, friends, and extended online networks (Himmelboim & Han, 2014). The vast advancement and proliferation of online discourses about health enable new and enhanced methods for relaying and receiving information in discussions about health, illness, and medicine. As such, interrogating how the public at large understands and takes up ideas about health and illness must extend to the media through which these notions are mobilized, as well as the kinds of official dictums against which these ideas are drawn.

These configurations of health discourses participated in and/or created by governmental or health-based institutions and popular media platforms provide key opportunities to elaborate on existing health and identity scholarship. Specifically, all understandings about cancer (and arguably any experience) inevitably intersect and interact with cultural and societal notions about identity, especially in regard to such

identity markers as gender, age, race, and class. Because contemporary “common” discourses acknowledge particular cultures, communities, and materialities typically not accounted for by the broader aims and leveling assumptions of official discourses, the intersections between these identity markers in common and official discourses suggest the importance of assessing these varied discourses in relation to each other because they can furnish valuable insight into how and why people understand and practice health and illness in the ways that they do, as well as why some campaigns and initiatives may be more or less effective (e.g., see Dubriwny, 2008; Oduro, Connor, Litwin, & Maliski, 2012; Pudrovskaya, 2010). For example, diagnoses of and discourses about each of the cancer types proposed for analysis here frequently associate certain cancer types with various combinations of these identity markers, resulting in the potential for rhetorical motifs that reflect and refract culturally inscribed notions of identity in regard to cancer diagnoses, treatments, and preventive measures. Common and official discourses, then, must be considered to illuminate how they are informed by cultural notions surrounding these identity markers in different ways. Vernacular discourses, of course, have relevance to and for these matters, in general and in relation to health. However, my project here is to assess and compare official and common health discourses as primary resources for individuals and communities—in particular, patients—in order to assess if common discourses, which, I aver, are more reflective today of broader exigent cultural imperatives and sensibilities than official discourses, diverge in significant ways from official discourses. I want to do this in order to potentially inform optimal health communication practices, as well as assert that we need to reevaluate the significance and role of common discourses in the production and consumption of information and power.



In order to mobilize this interest and operationalize the rhetorical construction of cancer and identity in these separate—yet related—discourses, breast, bladder, and skin cancers will serve as impetuses for mediated negotiations and discussions about these diseases, as well as the potential identities that are impacted and/or developed in relation to them.

Communication about science has become a common and encouraged phenomena in public discourse and the U.S. mass media since approximately the mid-1990s (Davies, 2008; Powell & Colin, 2008). A key part of the influx of attempts by science to communicate itself to publics is the dissemination of information about advances in health and medicine (Smith, Niederdeppe, Blake, & Cappella, 2013; Taylor et al., 2015). With research funding and support from the National Cancer Institute and other federal initiatives, cancer has become the most covered disease in health-focused news coverage and achieved a permanent position on the public agenda (Smith et al., 2013). Some health care providers and health promotion and education advocates laud the proliferation of information regarding cancer science in the public discourse for its ability to inform/empower the populace (Smith, Singer, & Kromm, 2010). Many cancer experts, however, prefer citizens to know primarily about prevention and early detection rather than all relevant cancer information that could be acquired or made available (Diviani & Schulz, 2011; K. C. Smith et al., 2010). Relatedly, whereas conflicting cancer-related information in the news has been found to help some viewers grasp the complexity of the disease and associated screening and treatment procedures (Dixon, Scully, Wakefield, & Murphy, 2008), this optimistic allusion to health literacy is not universally shared. Others—especially those conducting clinical and medical cancer research—have challenged this rosy view, averring that the impossibility of appropriately conveying

complex scientific information in mainstream formats and venues may in fact hinder research and/or treatment protocols (Smith, Singer, & Kromm, 2010).

Furthermore, public comprehension of cancer-related information in mass media has been found to be lacking, with consumers frequently overgeneralizing and confusing details specific to prevention and screening, thus leading to concerns that patient agency and cancer risk may be both over or underestimated by consumers (Mazor et al., 2010). Concerns about the accuracy and utility of health information in news coverage frequently center on the over/underrepresentation of health issues relative to their actual rates of occurrence, including cancer and related health scares, such that viewers gain skewed perceptions of cancer risk and prevalence (Ackerson & Viswanath, 2010; Bomlitz & Brezis, 2008; Jensen et al., 2014). Relatedly, concerns about the accuracy and focus of medical information in the news, including those stories based in part or in whole on press releases about health-related research, raise questions about the presentation and reception of cancer-related information, especially regarding the emphasis on disconcerting and attention-grabbing statistics (Taylor et al., 2015). Finally, segmented cancer messages in media—that is, those that are targeted toward specific or mainstream audiences—also vary in their content, suggesting that not all groups are receiving commensurate and adequate cancer information (Fishman, Ten Have, & Casarett, 2012).

In illuminating what “on the ground” understandings of respective cancers are, this study can inform researchers and health practitioners whether, in the first place, any disconnect between the science and public beliefs about cancer can be laid at the feet of “official” public communication about science, and if not, where and how the disconnects

occur. Perhaps most compellingly, this study can inform praxis regarding what information ought to be put out there. In other words, debate around the public discourse of science has typically revolved around very specific “official” messages, and sometimes interpretation thereof. This study comes at the issue from the other side: the mobilization of broader cultural, or “common,” understandings of cancer, regardless of where that information came from, which stands to inform health communicators how best to intersect with those everyday understandings.

### **Research Questions**

In order to assess and evaluate the differences and similarities between official and common discourses of health, attention must be paid to the existence, location, and mobilization of fissures between these discourses, especially as these fissures could indicate the pervasive discourses around particular cancers that patients are likely to have encountered and that may influence their perceptions of the disease, their experiences, and appropriate treatment. As such, this study will address and be guided by the following research questions:

RQ1: What are the differences, if any, between official and common health discourses of, respectively, breast, bladder, and skin cancers?

RQ2: How are health providers, patients, and specific cancers rhetorically characterized, respectively, within and across official and common discourses?

RQ3: How are individual and structural responsibility (or unaccountability) rhetorically mobilized across these different health conditions?

RQ4: What are the implications of these findings for health information, education, promotion, and intervention efforts?

## Theoretical Framework

The theoretical framework for this project is undergirded by scholarship in contemporary rhetorical theory, health communication, and media studies. Specifically, the interrogation of official and common discourses about cancer requires understanding about rhetoric as the mobilization of discourses, as well as critical approaches to rhetorical inquiry and health discourses.

### Rhetoric

While rhetoric is frequently (and understandably) conflated with the available means of persuasion, per Aristotle, or viewed as the handmaiden of the arts, the mobilization of the term has evolved beyond persuasion, politics, puffery, and prose. Lucaites and Condit (1999) note that current conceptualizations of rhetoric are often influenced and informed by the classical tradition's focus, which assumes rhetoric to be "the *public*, *persuasive*, and *contextual* characteristics of human discourse in situations governed by the problems of *contingency*" (p. 2, original emphasis). This emphasis on context and contingency is necessary for understanding rhetoric as "the human use of symbols to communicate" (Foss, 2009, p. 3). That is, context and contingency account for the fluid and dynamic nature of signs and symbols across cultures, thus allowing for increased inclusion of what counts as rhetoric. With the understanding that communication is inherently rhetorical (Brockriede, 1974), the following inclusive definition from Deluca and Demo (2000) is particularly salient and the one on which this study is based: rhetoric is "the mobilization of signs for the articulation of identities, ideologies, consciousnesses, communities, publics, and cultures" (p. 253). This attention to the productive nature of rhetoric indicates that realities and identities are constituted

through communication and that inquiry into these processes must examine the impact and long-term significance of rhetorical acts and their underlying symbolic processes (Campbell, 1974).

Foci for rhetorical inquiry—historically and currently—have frequently included public address (e.g., Palmer & Lucas, 2008), communication systems (e.g., Keränen, 2001; Mechling & Mechling, 1983), and mass communication processes (including production, distribution, and audience reception) (Condit, 1989; Condit et al., 2002) in order to examine how realities are articulated by and through these phenomena. Of particular importance for the current project is rhetoric’s attention to health imperatives and how cultural meanings of health, medicine, and illness are discursively and socially constructed through—among other “texts”—health policies, patient-provider interactions, news coverage, and international events (e.g., kairotic accounts of disorders emerging from and associated with specific conflicts and events, such as the association between active duty and Posttraumatic Stress Disorder) (Segal, 2008; Solomon, 1985).

Furthermore, how meanings about cancer are rhetorically mobilized and negotiated bespeaks the importance of interrogating tensions between dominant discourses and patient perspectives on the disease, especially as these tensions and discourses have the potential to impact health policy, news coverage, and common knowledge about cancer detection, prevention, and treatment (Keränen, 2010; Pezzullo, 2003; Trendowski, 2014).

Inquiry into the rhetorical dimensions of health communication encompasses assessment of the everyday disclosures and information-seeking endeavors of patients (Segal, 2008; Zoller & Kline, 2008), especially as these disclosures and mobilizations of health information emerge through representations of health, with narratives being a

primary example (Harter, Japp, & Beck, 2005; Sharf, 2009). How issues of health are negotiated by patients and providers through storytelling is often informed and impacted by the narratives and structures of the medical establishment (Carmack, 2010; Harter et al., 2005). Narrative medicine—the privileging of patients and their processes of narrativizing their orientations toward health—serves as a way to eliminate barriers between patients and providers, as well as approaches the medical encounter as a performance for all involved in health contexts (Charon, 2006; Langellier, 2009). Furthermore, how patients construct narratives about their health practices connects to sensemaking about health (Bute & Jensen, 2011). Relatedly, narrative as a medium for patient understanding about health information is not limited to just those stories that are shared within the medical context. Rhetorical scholars also attend to how mediated narratives inform patients about illness and disease (Zoller & Worrell, 2006) and the forms and functions of the medical establishment (Harter & Japp, 2001), as well as serve as “edutainment”—the embedding of health education in fictionalized narratives (Piotrow, Rimon, Payne Merritt, & Saffitz, 2003)—for audiences of popular culture texts like television series (Dutta, 2007; Gray, 2007).

### **Critical Rhetoric**

Critical rhetoric attends to the circulation of signs and symbols and the negotiation(s) of their meanings in a culture, but with increased awareness of and attention to the fluidity of power and the positionality of the critic. This orientation—which collapses the distinction between theory and method—seeks to demystify power and complicate rigid notions of ideology that fail to account for and negotiate the dynamic and fluid nature of power in everyday practices and performances (McKerrow,

1989). Comprised of two primary and complementary perspectives—the critique of domination and the critique of freedom—that each necessitate the understanding of power as both creative and repressive (Ono & Sloop, 1992), this orientation eschews the idea of power as a relatively stable and distributed entity that falls into the oppositional have/have-not binary, and engages in the negotiations of power in everyday practices and performances (as opposed to the excavation of ideology and the chipping away at power). Critical rhetoric, then, attends to how dominant discourses function as normalized and normalizing structures that hinge on notions of authority and order social relations so as to maintain their privileged positions in political, social, and cultural milieus and that, moreover, are in constant dynamic, fluid, and symbiotic relation with resistance and alterity to that end (McKerrow, 1989; Ono & Sloop, 1992).

In critiquing these structures, the critic creates a text representative of the cultural phenomenon under study by combining ideologically based fragments of culture that are inherently informed by—and often collapsed into—their historical context (Hasian, 2001; McGee, 1990). Examining this context requires critic collaboration rather than ideological exhumation. That is, critical rhetoric attempts to resituate the critic as a collaborator and seeks to remove the undertones of elitism inherent to the practice of declaring (and often romanticizing) the composition and material constraints of certain groups deemed to be oppressed (Charland, 1991). By necessitating that critics take the agentic audience and their own subject positions into account, critical rhetoric absolves the critic of being a definitively authoritative or objective voice on any given subject. Indeed, Ono and Sloop (1992) assert that “critics must highlight their contingency, not simply footnote it” (p. 51), thus providing a way for critics to productively acknowledge

and contextualize their perspectives and positionality, as well as account for the fact that they are part of the ideological system they are critiquing (McGee, 1990).

**Critical rhetoric and health.** With its attention to the circulation of signs and symbols and the negotiation of their meanings in culture, this orientation illuminates how discourses about health are negotiated in and across communities, as well as across media (Lupton, 2012; McKerrow, 1989). A rhetorical approach to the study and critique of health discourses is useful for examining how “common knowledge is produced and circulated in the varied discourses that underlie our cultural practice of health and medicine” (Leach & Dysart-Gale, 2011, p. 1), especially as they occur in the public and professional domains of mass media (Segal, 2005). By interrogating axes of power and reconfiguring how health is understood, critical rhetoricians privilege the voices of their participants and encourage them to speak for themselves, as well as critique how the social and political power of discourses surrounding health have the potential to privilege some perspectives over others (Lupton, 1994; Segal, 2005; Zoller & Worrell, 2006). The tensions involved in discussions about health and cancer are integral to illuminating how individuals take up ideas about their health; this understanding is imperative for effectively conveying accurate health information (Babrow & Mattson, 2003). This orientation is also useful for examining how cultural notions of identity take hold in and inform discourses about cancer, especially as these notions are demonstrated in vernacular discourses that are rhetorically drawn against official campaigns and initiatives about cancer. These varied discourses provide the opportunity to examine how rhetorical motifs potentially shape a form of reality that constructs or constrains how cancer is discussed (Condit & Bates, 2009).



Critical approaches—and specifically critical rhetoric—have been effectively mobilized in the interrogation of discursive constructions of health and illness, and how power is imbued within societal structures that promote and perpetuate disparities in care (Lupton, 1994). Drawing on notions of power and ideology to critique the structures that often subjugate and/or discipline the body into acceptance, conformity, and/or silence (Zoller & Dutta, 2008), critical scholars target the neoliberal constraint of health as an individual responsibility (Dutta, 2010) and attend to how standards of health are subjectively defined and utilized to police bodies (Jordan, 2004; Zoller, 2003). Lupton (1994) explains that bodies are inscribed by dominant discourses and relations of power are exercised through commonplace health and medical practices. Specifically, these constraining systems, standards, and practices alienate patients from their bodies and render them intelligible only through medical intervention, thus privileging the expertise of providers and medical technologies (Harter & Japp, 2001; Kroløkke, 2010). This is in keeping with Dutta's (2010) lobbying for the critical cultural turn in health communication which attends to the need for interrogating the exigencies that inform knowledge claims.

These practices that inform notions of health and medicine necessitate the understanding of culture as inherently fragmented and the practice of selecting fragments as texts for analysis (McGee, 1990). For example, Shugart (2011) assesses the rhetorically constructed narrative about obesity as demonstrated in cultural fragments in popular culture, and Brouwer (1998) utilizes a small number of interviews with gay men to illuminate the experiences of these men and their decisions to get HIV-positive tattoos. Furthermore, Hurt (2007) employs critical rhetoric to study how representations of

depression in national news discourse pathologizes female bodies as uniquely susceptible to depression and in need of a disciplinary mechanism because they are defective, passive, and sites of danger. Finally, by examining how news discourse constructed breast cancer and the expectations for the performance of breast cancer patient, Dubriwny (2008) attempts to find the balance between discursivity and materiality (a task which has proven difficult for critical rhetoricians who often deliberately avoid declaring and romanticizing certain groups as oppressed and impacted by rhetorically negotiated meanings of power). These tensions surrounding prevalent and varied understandings of health generally and cancer specifically are best examined in potentially competing, complementary, and circumvented discourses about health, medicine, and disease (Ono & Sloop, 1995; Segal, 2008).

Cancer, as the second leading cause of death in the United States, necessitates the examination and interrogation of how the disease is both experienced and discursively constructed by those traditionally involved with a patient's diagnosis, including patients, health providers, loved ones, caregivers (Centers for Disease Control and Prevention, 2016). Research into the interpersonal dynamics of communicating about cancer heavily emphasizes the patient-provider relationship and the impact of this relationship on patient adherence, satisfaction, and health outcomes (Brown, Stewart, & Ryan, 2003), especially as it pertains to improving patient-centered care (McCormack et al., 2011; Parker, Davison, Tishelman, Brundage, & The SCRN Communication Team, 2005), reducing disparities in cancer care (Dilworth, Higgins, Parker, Kelly, & Turner, 2014), and aiding in shared decision-making between patients and physicians (Shabason, Mao, Frankel, & Vapiwala, 2014). Narrative approaches to studying cancer privilege the sharing of

patients' stories about their embodied experiences with the disease (Ott Anderson & Geist Martin, 2003), while rhetorical approaches frequently assess the language used to discuss and define cancer and the implications thereof for those dealing with the disease, especially in regard to sense-making metaphors (Cobb & Starr, 2012), health education (Kline, 2007), and identity construction (Dubriwny, 2008). Relatedly, critical approaches interrogate the disease through the understanding that its diagnosis, treatment, and awareness are often stratified and experienced differently based on intersections of race, gender, age, socioeconomic status, and geographic location (Holt, Wynn, Southward, et al., 2009; Pezzullo, 2003; Pudrovskaya, 2010). Significant to the current project is the contribution it seeks to make to this literature base. While much critical health communication scholarship has established and confirmed the neoliberal and individual responsibility power dynamic in health communication—especially of the official/mainstream variety—I want to contribute by refining that work and examining precisely *how* individual responsibility is deployed, in potentially quite variable ways.

### **Discourse Production and Power**

Grounded in the critical rhetorical tradition and built on the tenets of interrogating the dynamic nature of power and ideology, Ono and Sloop's (1995) theorizing about the vernacular provides a nuancing of how we understand discourse from a critical rhetorical perspective to both differentiate and assert relations between official and vernacular discourse. Official discourse, as they allude, comprises those texts that construct history, delimit public space, and control understanding about dominant ideologies (Ono & Sloop, 1995). Vernacular discourse extends the orientation towards critiques of domination to include critiques of resistant discourses produced by localized

communities that are often oppressed and/or consigned to the margins (McKerrow, 1989; Ono & Sloop, 1995). With their emphasis on speech and resulting texts specific to these groups, Ono and Sloop (1995) privilege those discourses that reside within specific communities and frequently occur outside the mainstream media. While carefully avoiding the conflation of vernacular critique with liberatory practice, Ono and Sloop (1995) provide a useful framework through which to examine how culturally specific discourses circulate among communities that historically have been or currently are systematically ignored by dominant discourses and perspectives. Furthermore, examining these discourses “reveals how material conditions shape and motivate collective understandings of ourselves and the way we think things ought to be,” thus enhancing understanding about how marginalized communities convey meaning and demonstrate discontent with the status quo (Triece, 2011, p. 435).

The importance of vernacular discourses in the construction and enactment of identities and subject positions in marginalized groups is exemplified by Ono and Sloop’s (1995) theorizing about cultural syncretism and pastiche as a function of this practice. Oppressed groups practice the former by subtly protesting against dominant groups and ideologies by generating culturally specific discourses that affirm the subjectivities of the group; this practice is furthered by the borrowing or absorbing of fragments of popular culture into localized discourses, resulting in embodied practices that affirm the group while challenging dominant discourse (Ono & Sloop, 1995). Furthermore, definitions of what constitutes marginalization and which groups can reasonably be categorized as such have been expanded by research into online platforms and media technologies. Whereas Ono and Sloop (1995) center their focus on oppression of groups based on race and

ethnicity (especially as these identity markers intersect with cultural norms and discourses of gender), Hess (2009) argues that stigmatization operates as a form of marginalization and that social media and online users meet the criterion of resistance, rather than oppression. Thus, groups that take to the Internet to challenge official discourses and (re)form their cultural identities can productively be studied through increased “understanding of the discursivity of everyday resistance” rather than oppression and acknowledgement of divergence from the status quo (Hess, 2009, p. 415).

These critiques and extensions of vernacularity suggest the need for further critical inquiry that accounts for the changing media landscape. While mainstream news used to be appropriately understood as official or dominant, the changing nature of news media—including technological advancements in interactivity and engagement between producers and consumers—indicates the prominence and likelihood of consumer influence on content. Additionally, the increasing demand for and credence given to infotainment as a legitimate news source suggests that mainstream voices are diverging from the sole agenda-setting function of days past and instead engaging with cultural and social discourses desired by the public (Piotrow et al., 2003). As such, these mainstream discourses have the potential to serve as a good barometer of vernacularity in this historical moment, functioning not only primarily or exclusively as agenda setters (and thus official discourses) but as reflective of and resonant with prevailing cultural understandings and sensibilities.

**The current project: official and common health discourses.** This study is predicated on two primary needs: first, for continued and enhanced understanding about how people imagine health—in this case, cancer—and their relation to it; and second, for

enhanced applicability of common discourse in the context of a dynamic media landscape. To begin, the necessity of illuminating how individuals learn about and discuss their health in relation to cancer, as well as related medical treatments and preventative measures, is undergirded by the imperative to improve the construction, implementation, and (hopefully) reception of public health campaigns. Furthermore, how medical information—including that which pertains to illness and disease—is understood and acted on by patients and generally discussed in their day-to-day lives are key components to the successful navigation of patient-provider interactions (Lupton, 2012). As such, illuminating how various discourses about cancer intersect and perhaps even contradict each other has the potential to indicate mediated and interpersonal methods for physician intervention and participation in the coconstruction of knowledge about cancer. Thus, by attending to the cultural practices that discursively produce meanings of health and cancer, I take up Segal's (2005) assertion that rhetoric is useful for examining the functions of language, especially as they occur in the public and professional domains of mass media.

Regarding the production and dissemination of discourse as conceptualized from a critical rhetorical standpoint, I want to assert and develop the contemporary relevance of “common” discourse in relation to the foundational concepts of official and vernacular discourses. Although Ono & Sloop (1995) highlight nondominant discourses as giving voice to and making space for alternative perspectives—and thus merit theoretical attention—this approach relies on simplistic binaries of dominant/nondominant discourses, and mainstream/alternative media. As critical scholars frequently note (Ono & Sloop, 1992), the fluidity and dynamism of power render it impossible to approach the

distribution of power as a zero-sum game (Foucault, 2000). That is, power's productive nature gives rise to resistive practices and tensions that hinge on the negotiation of status, access, and control, resulting in a process of exchange rather than a simple determination of "haves and have-nots." This approach to power, then, negates any understanding of certain discourses being vernacular solely because they are relegated to certain communities, as well as raises questions about what constitutes localized communities, what constitutes marginalization in the globalized mediascape, and what constitutes dominance in the context of fluid power. Conceptualizations of dominant discourses, then, need to account for those relatively narrow and stable discourses that dictate meanings for—but do not draw from—cultural and social sensibilities in order to conceive of those vernacular discourses that do. Regarding health communication, official discourses are primarily prescriptive and dictate proper courses of action, so greater understanding about how vernacular discourses address similar messages is warranted.

Furthermore, the official/alternative binary fails to account for the complex means of content production and distribution, especially in the contemporary mediascape. That is, lay voices and localized communities are frequently (re)presented or incorporated in media that cannot be labeled alternative, oppositional, or resistive. For example, one does not need to read zines to learn how the public understands a governmental policy (though that would certainly be an option); one could simply read an Op-Ed essay in *The New York Times* and the attendant comments section to ascertain how official dictums are being filtered through and to the public. And, with ease of access to online content—and the growing access to the Internet domestically—concerns about the distribution of

vernacular content becomes complicated by the complexities of Web 2.0 and the fluid boundaries between public/private that are endemic to the prevalence of new media technologies. That is, lay perspectives have access to an unprecedented amount of platforms and cannot be easily confined to spaces shared solely by members of those unique communities. In light of these developments and pressing importance of the intersection between health and media/technology, this project is situated at the tensions, fissures, and negotiations between official and vernacular discourses about cancer across traditional and digital media.

Other scholars have noted these tensions inherent to the vernacular/official binary, and have worked to trouble and/or refine Ono and Sloop's (1995) original conceptualizations of discourses as official and vernacular. A primary critique centers on the simplicity and defined nature of the official/vernacular binary. As Howard (2008) notes, the changing mediascape—facilitated by the Internet and web-based technologies, as well as an increasing emphasis on participatory engagement from/with consumers—renders a clear distinction between vernacular and official/institutional discourses ambiguous. Additionally, much of Ono and Sloop's (1995) distinction relies on an oppressed/dominant binary that establishes the vernacular as originated by groups that are historically oppressed. However, this binary, too, has been challenged by scholars who posit that a better metric of “vernacular” is an emphasis on resistance or challenging of dominant discourses (Hess, 2009; Howard, 2005).

Relatedly, the notion of what constitutes “official” discourse has been similarly challenged, particularly in light of the ascension of participatory media. As previously discussed, Howard's (2008) complicating of the official/vernacular binary is largely



rooted in the understanding that institutional discourses lack definitive boundaries in the age of online interaction and the interrelationship between media producers and consumers. Bruns (2006) takes up this notion when theorizing about “produsage,” or “the collaborative, iterative, and user-led production of content by participants in a hybrid user-producer, or *produser* role” (p. 275). Theorizing about *produsage* is grounded in the assumption that the boundary between producers and consumers—that is, official and vernacular voices—has been broken down in the age of Web 2.0 and participatory media (Bruns, 2008). Other scholars have similarly attended to the enhanced role that audiences play in the production and dissemination of media content. Tandoc (2014) notes that web analytics have altered the ways in which journalists conceive of the audience and integrate their feedback in the process of constructing the news, resulting in enhanced attention to audience preferences and behaviors. Likewise, Lee, Lewis, and Powers (2014) assert that news editors are increasingly taking audiences into consideration in their gatekeeping processes. This emergent trend of increased reciprocal interaction between journalists/editors and consumers indicates a normalizing function such that desires and interests expressed by the latter will likely be taken up by the former (Lewis, Holton, & Coddington, 2014).

The news industry—often considered the conventional conduit for official discourses—has likewise experienced a breaking down of expertise and distinction between journalists and consumers. The aura of expertise that formerly surrounded the journalism field has been tarnished in recent years due to a variety of changes in journalistic practice, largely in response to a changing media field and financial imperatives. Specifically, training—and attendant availability and accessibility thereof—

for journalists has been reduced in recent years (Finberg, 2014). There has been a concomitant rise in citizen journalism, resulting in altered perceptions of journalism, journalists, and the rules that guide both in the context of citizen-driven journalism (Holton, Coddington, & Gil de Zúñiga, 2013). Particularly relevant to the current project is the changing dynamic and norms surrounding health and science journalism, primarily the absence of specialized training for health and science journalists that used to be standard practice and the cuts to funding for health and science journalists, often resulting in an increase in unspecialized freelance journalists (Schwitzer, 2009).

These broad changes and subtle shifts in our current dynamic mediascape demands a need for new ways to think about the official/vernacular and producer/user binaries by seeking a middle ground discourse that complicates these distinctions. Particularly in light of the media changes detailed above, this middle ground discourse best reflects Howard's (2008) conceptualizations of "common" discourse, or "the view of the vernacular [that] identifies its alterity as alternate to institutionally empowered speaking situations" (p. 494). Howard's (2008) conceptualization of the "common," however, is ultimately suspicious of mainstream news media and explicitly rejects it, largely on the grounds that it does not adequately attend to power imbalances inherent to media production. A dismissal of the "common," however, does a disservice for those wanting to attend to the fluidity of power and changing views on expertise that are prevalent in this historical moment. As such, I want to revive and revisit "common" and venture a reconceptualization of it as more amorphous and fluid—not quite the hybrid that Howard (2008) asserts is prevalent in the vernacular Web, but not quite a "lite" version of official discourse (arguably, per Howard, an even more hegemonic

deployment of official). All of the reasons noted above suggest that mainstream news, especially, challenges original conceptualization of the official/vernacular binary, and thus must be attended to in light of the unsustainable nature of this binary (despite original thinking that notes the symbiosis of these opposing perspectives/voices).

Although not the basis of my project, attending to classically vernacular discourses—online/audience/lay driven texts—compared to official discourses would indeed be a worthwhile endeavor were my project specifically to assess how lay audiences—while not interchangeable with vernacularity, more closely aligned with it per Ono and Sloop’s originary binary—understand health matters. However, while I am interested in assessing marked differences between institutional and broader cultural understandings of health for the improvement of practical health care and dispensation, I also want to explore my hypothesis regarding “common” discourses as qualitatively distinct from official ones, as well as how and where those differences inhere.

### **Critical Health Discourses**

Although Ono and Sloop’s (1995) framework is rarely taken up in inquiry about the rhetorics of health and medicine, the interconnections between official/institutional and vernacular discourses about health are nonetheless necessary to consider. As Keränen (2007) explains, it is often important to examine these interconnections because the combination of perspectives “can yield productive critical insights into rhetorical practice,” especially as they pertain to medical discourse (p. 181). In keeping with this idea is Keränen’s (2005, 2010) examination of how issues of trust, persona, and character were rhetorically mobilized in news discourse about the lumpectomy controversy in the 1990s and how these mobilizations shaped the controversy and public understanding

about it, as well as delimited roles for the breast cancer patients to adopt in the wake of the controversy. As such, the power and inevitability of these varied discourses to intersect and interact in productive ways suggests the need for further inquiry into the tensions between official and vernacular health discourses about cancer.

Taking up Keränen's (2007) argument that the interconnections between official and vernacular discourses have the potential to provide insights unique to their combined study, the current project seeks to engage these matters via the concept of "common" discourse, or mainstream public discourse broadly reflective of cultural imperatives and sensibilities that are not necessarily or arguably as likely to be apparent in official—institutional, state, or establishment—discourse. Messages and narratives about health have overwhelmingly been constructed and disseminated from health promotion and education campaigns. With the valuable and laudable goal of informing the public about productive health practices, these campaigns are generally oriented by and from the creators (and authority figures) who work in fields related to public health, health care, and promotion. Although some efforts have been made to design these campaigns to reflect the values and beliefs of the targeted communities, they generally are not of and by the communities themselves (e.g., see Holt et al., 2009). Rather, the culturally oriented and specific messages are still funneled through the formal channels and official discourses of governmental agencies, health promotion initiatives and organizations, and academic studies. The current project, predicated on the assertion that it is feasible to draw a distinction between official and common discourses, attends to how mainstream press outlets filter, mobilize, and make sense of information about various types of cancer, certainly as informed by conventional and persistent official discourses but also—

importantly—by changes to mainstream news media that have altered due to sweeping cultural and technological changes, ranging from shifting priorities and commitments to audiences, changes to production, consumption, and dissemination of information, and to participatory technologies.

### **Method**

A rhetorical approach is necessary for examining potential patterns of privilege, culture, and identity that are articulated in discourses about bladder, breast, and skin cancers across media, and specifically a critical rhetorical approach is the most advantageous way of examining how these patterns are demonstrated in and against official and common discourses. Blurring the line between theory and method, critical rhetoric allows for the interrogation of texts and contexts through careful attention to the material relevance of rhetoric on bodies (McKerrow, 1989). Utilizing this approach requires the consolidation of fragments of culture—in this case, public health information, health campaign materials, and online news content—in a process that creates rhetoric at the same time the rhetoric is assessed. Furthermore, these fragmented texts are created by/within their contexts and informed by factors both internal and external to their production, including, for example, popular culture, politics, and social media user interfaces (Hasian, 2001; McGee, 1990). As a critic, then, I am a collaborator in the creation of these texts and thus must be self-reflexive about the assumptions that result from my subject position(s) as a scholar and that inform my text selection, methodological choices, and analytical approach (Louis & Barton, 2002). Indeed, Ono and Sloop (1992) assert that “critics must highlight their contingency, not simply footnote it” (p. 51), thus providing a way for critics productively to acknowledge and

contextualize their perspectives and positionality, as well as account for the fact that they are part of the ideological system they are critiquing and that one's critiques are complicated by other possible interpretations (McGee, 1990).

The texts proposed here for analysis provide insight into how governmental entities and health organizations discursively construct various cancer types, as well as how mainstream news media discuss these diseases. Specifically, public health campaigns, awareness programs, and education resources about breast, bladder, and skin cancers will constitute the official discourses under examination (and will be gathered exclusively through the websites of the entities in question). News discourses from national newspapers and newsmagazines—all available and gathered online—as well as articles from popular online news sources—for example, *The Huffington Post*—will comprise the common discourses that circulate around and reflect the experiences with and perspectives on cancer that resonate with the public. As mainstream, accessible engageable texts—which feature, for instance, comments sections and “like” and “dislike” features—these texts are ideal for this project insofar as permeability and participation (specifically as relevant to audiences) are integral to their public presence, and thus poised to be responsive or reflective to audiences and, more precisely, their cultural articulations in relation to phenomena at hand.

Assessing the data sets for this project through a critical rhetorical lens requires systematic and repeated viewing and reading of the texts in order to identify patterns. Interest in each cancer type under examination here is mobilized through two distinct data sets specific to each disease, with those data sets encompassing official and common discourses. Determining the potential differences and similarities in how these disparate

discourses construct cancer types necessitates systematic reading in order to illuminate patterns, repetitions, and emphases regarding the nature of each cancer, especially as the discourses about it reflect and intersect with cultural notions of identity and neoliberal emphases on responsibility. As such, care must be taken to highlight how specific perspectives of and positions in relation to cancer are represented, included, silenced, or even absent in the data sets, and what these presences and absences suggest about configurations of how health are discussed in and across media, and furthermore appear to be taken up in cultural contexts and communities.

Distinguishing between official and common discourses requires attention not only to the origins of texts, but also the design of the messages and means of distribution. Official discourses—public health campaigns, health foundation websites, and governmental resources, among others—are designed as intervention- and education-based information resources that privilege the outcome of improved informed decision making for consumers (Holt, Wynn, & Litaker, et al., 2009). As authoritative voices that wield the power of science and medical technologies to substantiate their claims, these discourses function as the official version (or the master narrative) about cancer that all other media outlets must repackage for their readers or must be made sense of by the general public. If vernacular discourses are associated with localized speech (Ono & Sloop, 1995), texts that are drawn against and have the task of digesting and reformatting these official discourses *and* that invite and incorporate, in a contemporary mediascape, audience engagement and response, comprise a common discourse that reflects culturally received understanding and articulations, as well.

Written at an approximately 11<sup>th</sup>-grade reading level, newspapers have long

fulfilled their role to package and present information to readers in language that reflects the preferences of the audience and renders the content as accessible as possible (in order to benefit commercially, of course; Conboy, 2010). Relatedly, magazines—both news and popular—are expected to be produced under the same banner of accessibility and readability, and thus represent the general tastes, cultural sensibilities, language, and information preferences of the general population. Finally, the accessibility of news stories in online formats has proliferated such that the availability of this information is no longer reserved for those who can afford subscriptions or newsstand prices.

The decision to categorize these texts as common is grounded partly in the popularity and prevalence of edutainment and infotainment in a for-profit media industry context (Piotrow et al., 2003) and partly in the characteristics of cultural syncretism and pastiche (Ono & Sloop, 1995). The practices and products of edutainment assist—often through careful scripting—health practitioners in their quest to promote and proliferate accurate health information to those who may otherwise not be exposed to such information, and do so through the inclusion of health-based information in entertainment and informative contexts (e.g., see Dutta, 2007). Cultural syncretism and pastiche as a function of it allow both for representation of counterhegemonic perspectives and subtle incorporation of dominant ideas and discourses to aid in constructing and communicating about identities and subject positions unique to specific communities (Ono & Sloop, 1995). Pastiche, then, allows for the appropriation of elements from dominant discourses and other cultural fragments to render new subjectivities and ways of knowing and talking about phenomena (in this case, cancer).

In order to carry out my analysis, I visited, read, and archived the websites and



materials published by the public health campaigns and health resources (all of which constituted the official discourses under examination here). Collecting my “common” discourse data necessitated a reliance on several primary research databases purchased by the University of Utah’s Marriott Library: Newspaper Source Plus, ProQuest, EBSCOhost, and *New York Times* Historical Newspaper. These databases were used due to their extensive publications index, as well as the fact that many news publications websites require subscriptions in order to access more than a handful of articles per month (*The New York Times* is a primary example of this type of proprietary website). For each respective data set, I searched the aforementioned databases for the following terms: “breast cancer,” “bladder cancer,” and “skin cancer,” and I limited my search to the specific date range of January 1, 2013 to December 31, 2015 (in order to gather sufficient data for my bladder cancer chapter, I extended the date range from January 1, 2012 to December 31, 2016). In order to productively limit my data set to only those articles that directly discussed these cancer types, I eliminated all articles that only briefly referenced these respective cancers, as well as all obituaries and duplicate articles. My search for “breast cancer” yielded 247 articles total; when transferred to a Word document, this data resulted in 645 single-spaced pages (once all front matter was removed from each article). My search for “bladder cancer” yielded 330 articles; when transferred to a Word document, this data resulted in 443 single-spaced pages (once all front matter was removed from each article). My search for “skin cancer” yielded 130 articles total; when transferred to a Word document, this data resulted in 307 single-space pages of data (once all front matter was removed from each article). Analyzing this data required me to read each article closely and attend to how these cancers were

characterized and discussed therein. Themes emerged that were refined and revised in order to capture the primary characterizations and understandings of these cancers.

### **Preview**

The following sections build on this methodological foundation to address the importance of studying discourses about breast, bladder, and skin cancers, as well as the specific data that will be collected and analyzed via close and repeated reading. Studying cancer discourses necessitates a productively narrow focus that allows for the examination of the potential intersection of notions about gender, age, race, and class as they possibly manifest in official and localized discourses, as well as how imperatives of individual responsibility are potentially mobilized. The prevalence and severity of breast, bladder, and skin cancers render these diseases and their attendant discourses particularly relevant for study at this historical moment as each of them holds a unique position in the national narratives about the fight against cancer (Keränen, 2010). As such, each section below explains and justifies the selected texts that represent official and common discourses about each cancer type, as well as why these discourses are important to examine across different media types.

### **Breast Cancer**

As the most prevalent cancer amongst women in the United States (Centers for Disease Control and Prevention, 2015)—resulting in approximately 230,000 new diagnoses every year—breast cancer has been on the public agenda since Betty Ford’s radical mastectomy made headlines in the 1970s (Dubriwny, 2008). It is the most covered cancer in news (although its actual rate of incidence puts it second behind male

reproductive cancer) (Jensen, Moriarty, Hurley, & Stryker, 2010) and public perception of its prevalence is commensurate with the actual rates of annual diagnoses (Jensen et al., 2014). The continual visibility of breast cancer—reaffirmed every year in October by the proliferation of pink products in honor of Breast Cancer Awareness Month—has been heightened by the recent spate of news coverage focused on the BRCA1 and BRCA 2 gene mutations and the Supreme Court’s ruling that Myriad Genetics’ patents on the mutations were unconstitutional (Pollack, 2013). Further garnering attention for the disease has been the high-profile diagnoses and treatments (including prophylactic) undergone by such public figures as actor and activist Angelina Jolie and actor Christina Applegate in 2013 and 2008, respectively (Board, 2013).

Due to its prevalence and consistent national attention, breast cancer posed the challenge of productively narrowing the texts collected and combined for study. In order to attend to how breast cancer is rhetorically constructed by the professional (i.e., official) and public (i.e., common) sectors of cancer information in the United States, these discourses were examined across print news and public health campaigns and initiatives. Specifically, the official discourses about breast cancer analyzed here included programs funded by the National Breast Cancer Foundation and campaigns funded by the Centers for Disease Control and Prevention. Texts featuring common discourses were those that privilege and facilitate lay discussion about the disease via national news coverage and via texts that can potentially fall under the rubric of education-entertainment (or “edutainment;” e.g., entertainment news; Piotrow et al., 2003).

First, the National Breast Cancer Foundation provides a variety of educational resources and programs promoted as aiding patients in successfully navigating their

breast cancer diagnoses from early detection through the process of managing treatment costs. Founded in 1991, the Foundation features the Beyond the Shock program which is a free interactive application that patients download on their smartphones, tablets, or laptops in order to receive educational resources and support throughout all stages of diagnosis, treatment, and recovery. The application-based program also serves as an educational resource for family and friends of breast cancer patients and for physicians to be involved with the dissemination of information (National Breast Cancer Foundation, 2015).

Second, the Centers for Disease Control and Prevention—as the government agency that wields the expertise and resources of scientists and disease detectives to maintain national health (and ostensibly security)—provides two campaigns centered on raising awareness about breast cancer. First, the Right to Know campaign targets specifically women with disabilities and promotes screenings for this frequently underserved community; in doing so, the campaign addresses common barriers to knowledge about the disease and provides printed and electronic materials that correct for misperceptions and erroneous information about diagnosis rates, likelihood, screening procedures, and treatment (Right to Know, 2014). Finally, the Bring Your Brave campaign targets women under 45 years of age in order to educate this group—who is diagnosed with less frequency—about the importance of family history and the exploration of risk factors that can contribute to diagnoses in young women (Bring Your Brave, 2016).

In contrast to these official governmental and organizational discourses that frame breast cancer through their authoritative and vested interests in the disease, common

discourses are prevalent in popular culture and national news media. As the past 5 years have been marked by heightened interest in breast cancer prevention and treatments (for example, Angelina Jolie's Op-Ed essay in 2013 and SCOTUS revoking the patents on the BRCA 1 and BRCA 2 gene mutations), popular press and mainstream discourses about the disease provide important sites through which consumers learn about health and illness (Lupton, 2012). Inclusive of mainstream media, the following texts all include lay perspectives of breast cancer that are drawn against the official discourses distributed by governmental, nonprofit, and health organizations, thus allowing for the examination of possible fissures in how different media potentially facilitate differing discourses about the disease. Specifically, print news coverage published between 2013 and 2015 will be selected to reflect a variety of genres, target audiences, and ideological positions, including *The New York Times*, *USA Today*, *Time*, and *People*. Although these texts encompass distinctive genres—including more or less “legitimate” news sources and celebrity-based fare, for example—they can indeed be apprehended as common because they interpret official discourses of health and illness for public audiences in ways that also draw on resonant imperatives of culture and identity, especially insofar as these texts seek to relate to their audiences for continued circulation and profits.

### **Bladder Cancer**

Unlike breast cancer and its firmly embedded position on the public health agenda, bladder cancer is a largely ignored disease in the United States, earning the unfortunate designation as “the invisible cancer” because of the historical lack of private, public, and governmental funding and attention given to it (Johns Hopkins University, 2014). As one of the top three least-funded cancers (alongside thyroid and stomach)

(Jensen et al., 2014) and primarily affecting older white men, bladder cancer poses a unique fiscal challenge to patients and providers: it is the most expensive type to treat per patient due to high recurrence rates and the constant monitoring and treatments that are required for the duration of the patients' lives (American Cancer Society, 2014; Bladder Cancer Advocacy Network, 2014; Lotan et al., 2009). Despite its prevalence as the sixth most common cancer type (Jensen et al., 2014) and the annual diagnosis of 75,000 new cases (American Cancer Society, 2014), bladder cancer is perceived to be the least common type by the public (Jensen et al., 2014) and is one of the most underrepresented cancer types in the news (Jensen et al., 2010).

Despite the prevalence and severity of this disease, no current public health campaign exists in the United States.<sup>1</sup> As such, the official resources available for bladder cancer patients—and which constitute the official discourses under study here—include the Websites of health foundations and networks, including the American Bladder Cancer Society, the Bladder Cancer Advocacy Network, and the American Cancer Society's online resources about the disease. Drawn against these texts are those that privilege and result from the voices of bladder cancer patients, although common (not to mention vernacular) discourses about the disease are as conspicuously minimal as official discourses. Specifically, national news coverage of the disease will be assessed for its construction of the disease and related processes for prevention, diagnosis, and treatment.

Founded in 2007, the American Bladder Cancer Society (whose slogan is, tellingly, “Forget Us Not”) is a nonprofit organization with the mission of helping patients “form questions in order to have more informative conversations with your

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<sup>1</sup> North American attention to bladder cancer is present in Canada's public health campaign and support network.

medical team” (American Bladder Cancer Society, 2016g). Organized and operated by bladder cancer survivors, the Society’s website offers visitors information based on both personal history with the disease and resources for enhancing the patient-provider encounter. Based on this aim, the website provides a series of educational resources for patients who need assistance in finding treatment centers, support communities, and information about the various kinds of diagnoses, as well as resources for caregivers and those interested in volunteering and raising awareness. Even though this is a patient-generated effort, it nonetheless functions as official because of how it positions itself as a resource for patients, particularly an instructive resource that guides patients in talking with their medical providers about their diagnosis and health—in other words, it serves as an authorial source that organizes patients and providers into formalized social relations.

Relatedly, the Bladder Cancer Action Network (BCAN) has advocated for the advancement of research and support for patients since its creation in 2005. With their aim of an eventual cure, the BCAN supports a wide range of awareness efforts and research initiatives, as well as features a variety of educational resources to aid patients in understanding their diagnoses and possible treatments. A unique feature of the website is its attention to women and diagnoses common to them. Because it most frequently occurs in older (white) men, bladder cancer is generally associated with this specific demographic group. As such, BCAN’s attention to the experiences unique to women is noteworthy and useful for inclusion in order to interrogate how notions of gender play out in cancer discourses.

The final official channel of information is the bladder cancer section of the American Cancer Society’s (ACS) website. In keeping with their ethos to provide

comprehensive cancer care information, the ACS website features extensive tools and resources tailored to specific cancer types, as well as educational forums in which to learn more about the research being done to cure variations of the disease. The American Cancer Society is the most recognizable and oldest of the official channels of information included here, and as such, the resources and information provided therein reflect original research that is likely to be reiterated in the other aforementioned official discourses about the disease.

Aligning with my previous discussion of common discourses about breast cancer, the discourses about bladder cancer are similarly mainstream in order to assess how the limited official ideas available about the disease potentially feature in and/or get negotiated by a wide variety of national news sources. Although collected from the same 3-year span of time as news coverage of breast cancer, broader inclusion of types of news sources were taken into account here due to bladder cancer's traditional absence from the public imaginary. As such, the texts selected for analysis included both those assessed for breast cancer—*The New York Times* and *USA Today*—as well as additional newspapers, newsmagazines, and new amalgamator sites—specifically, *USA Today Magazine*, *Los Angeles Times*, *Wall Street Journal*, *Huffington Post*, *Rolling Stone*, *Chicago Tribune*, *The Washington Post*, *Reuters*, and *Boston Globe*. These publications provided the opportunity to assess how different identities were constructed in relation to the disease and its related processes, particularly in light of how limited public discourse and understanding are about the disease.



## **Skin Cancer**

With annual diagnoses occurring at similar rates as bladder cancer, melanoma of the skin impacts approximately 74,000 new patients every year, is one of the most common cancer types in the United States, and causes the most deaths among types of skin cancer (National Cancer Institute, n.d.; Skin Cancer Statistics, 2015). Unlike bladder cancer, however, skin cancer is perceived to be slightly more common than it actually is (Jensen et al., 2014) and featured in more news stories than other types that occur with greater frequency (Jensen et al., 2010). The prevalence of skin cancer news coverage, however, is understandable when considering that the less severe and mostly curable nonmelanoma skin cancers—basal cell and squamous cell carcinomas—occur with such great frequency that they are not tracked by central cancer registries (Skin Cancer Statistics, 2015). As such, the breadth and depth of severity posed by all three kinds of skin cancer render the disease to be of utmost relevance for study.

Frequently the center of media attention at rates more closely resembling that of breast cancer than bladder cancer, skin cancer features a variety of official initiatives to prevent and detect the development of the disease. Comprised of three types that render it the most common cancer type—and one of the most deadly in the case of melanoma—skin cancer and its widespread impact yield extensive lay discourses about safe sun practices and related activities, as well as cancer diagnoses and treatment. As such, the potential data for this section—though relatively plentiful—are narrowed to campaigns and social media posts. The official discourses under examination here and detailed below all target specific aspects of skin cancer: teaching self-detection practices for spotting melanoma via the #GetNaked and Check Me Out! campaigns from the

Melanoma Research Foundation; encouraging abstention from self-tanning via the Go With Your Own Glow campaign from The Skin Cancer Foundation; and instructing in sun safety awareness behaviors via the annual Don't Fry Day from The National Council on Skin Cancer Prevention. Compared to these discourses are those published in mainstream news sources in order to assess how ideas about the disease are filtered to the public through news and entertainment news outlets.

The Melanoma Research Foundation (MRF) features two related public awareness campaigns designed to encourage self-detection practices. The #GetNaked campaign utilizes social media parlance in the marketing of their materials about performing self-exams to detect skin abnormalities. Although the campaign website reaffirms that melanoma does not discriminate based on age, the emphasis on and use of social media engagement to share and encourage the practice of self-exams—and thus “getting naked”—seems to target younger audiences. Social media users are encouraged to use the eponymous hashtag, #melanoma, and include the MRF's Twitter handle in tweets about performing self-exams, using and sharing MRF resources, and changing one's profile picture to the ad for the campaign. Relatedly, the Check Me Out! campaign emphasizes patient participation in the cancer detection process (rather than relying on physicians) and provides charts and a video encouraging people to regularly check and monitor their moles for changes and abnormalities.

Founded in 1979, The Skin Cancer Foundation has pioneered many awareness and education initiatives to assist the public and the medical profession in understanding the disease, modifying cancer-causing behaviors, and engaging in early detection practices. This attention to education, action, prevention, and detection is largely

prompted by the understanding that this disease is primarily caused by lifestyle choices and can reasonably be prevented by related choices. A relevant campaign that reflects this perspective is the Go With Your Own Glow campaign. Ostensibly attempting to harness the norms of femininity in the United States to discourage tanning, the Go With Your Own Glow campaign targets women with the message that natural skin hue is preferable and fashionable. The extensive campaign website features fashion magazine-style ads used in print and digital platforms, sun safe beauty tips, antiaging tutorials, and news resources for female consumers interested in learning more about the harmful effects of indoor and outdoor tanning.

The National Council on Skin Cancer Prevention has declared the Friday before Memorial Day to be Don't Fry Day and provides an extensive range of awareness and educational materials to promote sun safety and skin protection. The campaign targets all ages at a time that is generally considered to be the beginning of peak sun exposure months in the United States and promotes behavior modification through antitanning ads, incorporation of the American Cancer Society's awareness campaign for healthy sun exposure practices ("Slip! Slop! Slap! and Wrap"), and a library of sun safety fact sheets and URLs to aid in decision making. Similar to the #GetNaked campaign, Don't Fry Day encourages a social media presence for the campaign and even provides sample tweets—all of which contain #DontFryDay, of course—for people to post in support of sun and skin safety behaviors.

Contrasting with these official dictums for how to deal with sun safety and skin cancer is mainstream news coverage. This common collective discourse, even as it might reflect official discourse, also engages resonant cultural sensibilities that shape how

audiences understand and respond to skin cancers, and as such serve as the filter through which many official ideas about skin cancer get filtered to the public. Similar to common discourses about breast and bladder cancers, skin cancer coverage was assessed via 3 years' worth of news coverage from *The New York Times*, *USA Today*, *Time*, *People*, *Health*, and *Men's Health* in order to illuminate which ideas about sun safety, skin care/damage, and cancer get taken up and promoted to the public via both "legitimate" and "edutainment" publications.

### **Contribution**

Predicated on the assumption that how common discourses rhetorically construct cancer is different from official discourses about the disease, this study will seek to contribute to current understanding about health, rhetoric, and media studies in three primary ways. First, this study seeks to contribute to critical rhetorical studies. By examining the potential distinctions between official and common discourses in health contexts, this study will attend to the ways in which these potential distinctions indicate the possibility for mainstream media content to be reconceived of as common, particularly in light of how mainstream news is beholden to—and ostensibly impacted by the online capabilities of engagement with—consumers. In this way, official discourses will be those that define the status quo, while common discourses are expected to work with and against the ideas outlined by governmental and institutional structures in the process of (re)articulating these ideas for lay audiences. In particular, this study seeks to assert and refine a "third way" or a middle ground: a "common" discourse, originally articulated by Howard (2008). Although at the time of his writing he found it suspect and effectively a variation of official discourse, I argue for its validity, salience, and

significance as a notable discourse that incorporates both conventionally vernacular and official discourses to evince a distinctive discourse redolent of broad cultural sensibilities and imperatives that cannot, in this historical moment, be so easily dismissed, especially if and as venues of common discourse—mainstream news outlets, for instance—continue to serve as a resource for cultural and practical knowledge.

Second, this study will contribute to the health communication literature that pertains to the rhetorical construction of patients. Specifically, it will examine how discourses about cancer potentially construct patients as responsible for their diagnoses and treatments, as well as construct them in relation to medical providers (who are assumed likewise to be rhetorically constructed in specific ways) and the disease generally and specifically. It is useful to interrogate the established observation that individual patient responsibility lies at the heart of discourse around health broadly in the United States and attend not only to not what this means, but how it is mobilized in each of these discursive articulations of these common cancers. Additionally, the types of cancer included here for study—breast, bladder, and skin—are all situated within tensions that highlight the material impacts of these diseases on certain bodies (e.g., bladder cancer affecting predominantly older white males and the influence of hegemonic masculinity on gender norms and expectations in the U.S. imaginary), as well as on interactions with medical providers.

Finally, this study will contribute to extant literature on public health campaigns, in particular as articulated via contemporary technologies. By illuminating how mainstream public ideas about cancer detection and prevention are negotiated and drawn against health campaigns, in particular as relevant to divergences between them, this

study has implications for how future public health campaigns are constructed and promoted to target audiences, especially in regard to how ideas about patients, physicians, and the medical establishment are constructed in potentially divergent ways. Understanding broad popular conceptions and mobilizations of these cancers, as well as providers and patients in relation to it, can inform appropriate and productive engagement with and treatment of patients with these cancers, particularly engaging them in terms of the cancers but also in terms of how patients perceive it, themselves, and medical treatment.

## CHAPTER II

### BLOODIED AND BOWED: PATIENT AGENCY AS CASUALTY OF WAR (ON BREAST CANCER)

In the 4 decades since President Richard Nixon declared war on cancer in 1971 and First Lady Betty Ford's subsequent well-publicized radical mastectomy in 1974, breast cancer has become—and remained—a highly visible and enduring battlefield on which the war is waged (Dubriwny, 2008). As one of the most common cancers among women in the United States—as well as the most covered cancer in the news—breast cancer and attendant discourses about it necessitate critical inquiry into how both authorities and mainstream news understand and engage the condition, particularly as they impact providers and patients (Centers for Disease Control and Prevention, 2015; Jensen et al., 2010). While discourses about breast cancer are indeed common owing to the disease's seemingly permanent position on the public agenda, they are particularly relevant to study now in the wake of high profile news events about breast cancer, including the Supreme Court's overturning patents on the BRCA 1 and BRCA 2 gene mutations and actor/philanthropist Angelina Jolie's *New York Times* essay about her prophylactic mastectomy. In this context of continued—and arguably recently heightened—attention on breast cancer, critical interrogation of public discourses about the disease is necessary in order to understand how public representations and understandings of the disease are constructed and circulated, and potentially drawn

against one another; this type of interrogation ensures that health services/practitioners have awareness of and appreciation for how patients may understand and engage breast cancer in order to ensure effective treatment.

In this chapter, then, I analyze how breast cancer, patients, and providers—as well as prevention, diagnosis, and treatment—are rhetorically characterized in public health campaigns, as well as how these ideas are mobilized in mainstream news discourses about breast cancer, in order to apprehend how these articulations about breast cancer potentially overlap, mingle, and/or diverge. The importance of this inquiry is located within its potential to illuminate how the predominant voices in public discourses about breast cancer are constructing the disease and how these findings may impact the everyday treatment of patients, as well as the future construction of subsequent public health campaigns.

### **Official Discourses**

Official public health campaigns and initiatives are most often crafted to address a health issue or condition that is perceived as relevant in either its prevalence or danger (or both). Generally informational, these official discourses tend to instruct consumers about prevention, detection, treatment, and the like. This information is inevitably rhetorical, and thus engages cultural perspectives and discourses regarding how we perceive the condition in question, the people affected by it, and the cause and redress of the condition. Thus, we often tend to understand health issues based on how they are constructed by public health campaigns (e.g., obesity as an epidemic that targets children per the prominent the Let's Move campaign, which further identifies parents as the responsible parties at an individual level and obviates a role for structural agencies).



As one of the most prevalent, visible, and funded cancers, breast cancer naturally is at the center of a multitude of initiatives and public health campaigns, and thus the selected discourses included here for critical interrogation were selected for their unique perspective on the disease. First, the Beyond the Shock program—funded by the National Breast Cancer Foundation—offers a free interactive application with education resources for breast cancer patients, supporters, and medical providers, thus offering triangulated content and perspectives; this program is studied primarily through the educational videos offered on the website that explain the disease in lay terminology. Second, the Right to Know campaign—funded by the Centers for the Disease Control (CDC)—is the first breast cancer campaign designed to target women with disabilities in order to improve the quality of screenings and care women with disabilities receive. Finally, the Bring Your Brave campaign—also funded by the CDC—is likewise unique in that it targets young women (those under 45 years of age) in order to educate them about their potential risk factors for getting the disease at a young age (while rare, diagnoses in young women are a growing problem).

These health-based based programs and campaigns are important to study due to their authorial status and credibility, as well as their uniqueness and prevalence; the former program is one of—if not the—first free comprehensive and interactive online guides for dealing with a breast cancer diagnosis, and the latter campaigns are two of the CDC's most prominent initiatives (and ostensibly some of the most visible and accessible, as well). When analyzed together, these official discourses position breast cancer, and how to understand it, as an individual issue that hinges largely on the initiative taken by patients to be active agents in control of their health and the optimism

to deal with the disease, regardless of its severity, thus reifying the understanding that patients are ultimately in control of their emotions and outcomes (if not necessarily their bodies).

### **Mobilization of Agency**

Perhaps not surprisingly, public health campaigns about breast cancer primarily focus on constructing plans of action for patients, resulting in an emphasis on those aspects of disease detection, prevention, and treatment that can be gauged and impacted by the decision-making processes of patients. These campaigns, then, render individual agency as natural and to be expected, and thus articulate how agency can—and should—be mobilized by patients. Enacting control over one’s health—and possible disease—hinges on the abilities of patients to monitor their risk for cancer and their bodies as potential sites of disease and to manage their emotional care. These enactments of agency construct the image of a breast cancer patient as ultimately in control of her diagnosis and emotions, if not necessarily her body.<sup>2</sup>

**Monitoring bodies.** As the primary imperatives of most public health campaigns are to raise awareness and aid in prevention, the emphasis placed on monitoring the body as a potential site for disease and unease is indeed common for the breast cancer campaigns analyzed here. How the body is to be monitored, per these campaigns, reinforces the idea that the female body is always already at risk, and thus women must be vigilant agents in the prevention and detection of cancer. The process of monitoring

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<sup>2</sup> While men can get breast cancer, less than one percent of all diagnoses are in men, and thus the disease overwhelmingly affects women, so public discourses about it, including official discourses, assume a woman patient (“Male Breast Cancer Treatment,” 2016).

bodies at risk is articulated as an individual effort that is accomplished both alone and in conjunction with the medical establishment, with both paths underwriting the primary role individual women must play in the fight against potential and actual breast cancer. Additionally, by apprehending women in this role, these discourses objectify the female body by necessitating constant inspection and interrogation of it by both the patient and the overseeing medical expert who is automatically granted this authority over the female body. This objectification operates to accentuate the risks inherent to a female body and renders it suspect, and thus naturally in need of vigilant oversight.

A key element in the process of monitoring bodies at risk is the initiative to do so without prompting from medical providers and in service to others, suggesting that health maintenance and disease prevention are inherent practices that should be innate to women as the nurturing epicenters of familial and social circles. The cultural presumption that women are vanguards of health—both their own and others’—underscores that this propensity towards health maintenance is necessary because the female body is a suspect object, and thus must be monitored closely for any possible unruly changes that might negatively impact others (for example, family members). In a poster for the Right to Know campaign, a breast cancer survivor is featured and credited with centering the locus of responsibility internally:

Helen credits screening and early detection with still being alive today, and reminds us to take care of ourselves first if we want to be there for our loved ones. (Right to Know, 2016b)

In this case, monitoring a body at risk necessitates not only agency in the form of personal initiative (for example, screening at home and/or at a doctor’s office), but also agency in the form of maintaining personal responsibility to others (that is, women must

remain healthy so as to care for others). Thus, personal responsibility becomes synonymous with empowerment in that women are assumed to be in control of suspecting and inspecting their bodies, as well as preserving their utility for others. Concomitantly, this purported empowerment reifies the understanding that the female body is suspicious and likely to become unruly if control is not seized by the female patient. Although implied here, the involvement of the medical establishment is mostly obfuscated, suggesting that it serves more as a supplement to the directives of patients, rather than a governing body. This notion of medical expertise operating silently in the background is reinforced in the Bring Your Brave campaign:

To manage her risk for developing breast cancer, Amy gets regular screenings. She considers knowing her breast cancer risk a “head start” in staying vigilant with regard to prevention—truly empowered by learning her risk.  
(CDCBreastCancer, 2016a)

In discussing both regular screenings (ostensibly performed by medical providers) as opposed to at-home surveillance and learning about risk as a form of prevention, this campaign reflects the Right to Know campaign in both the obscured position of medical providers in this woman’s care, but also the need for women to take control of their futures (for their families, feelings of empowerment, etc.).

These campaigns also frequently attend to the increased risk inherent to women with BRCA 1 and BRCA 2 gene mutations, and thus further center the disease as an individualized problem due to the genetic makeup and/or genealogical history of the patient. By locating the need for monitoring within the genetic composition of women—and in the process underwriting the notion that many women’s bodies are sites of known and unknown threats—these campaigns reinforce the understanding that breast cancer is an individualized disease that emerges from within. For example, the Bring Your Brave

campaign highlights the personal steps taken to monitor and reduce the possible dangers that could result from genetic mutations:

To manage her breast and ovarian cancer risk, Marleah currently undergoes surveillance and makes healthy lifestyle choices like maintaining a healthy weight, exercising, and limiting her alcohol intake. Because BRCA2 gene mutations are associated with a higher risk for melanoma, the deadliest kind of skin cancer, Marleah also visits a dermatologist every year for a skin exam. She enjoys outdoor activities while protecting her skin. (CDCBreastCancer, 2016d)

Through the assistance of medical intervention in the form of genetic testing, this potential breast cancer patient (or “previvor,” in BRCA1 and BRCA 2 parlance) highlights the role of personal initiative in combatting her risk for developing cancer. The knowledge provided by medical intervention—that is, genetic testing and counseling, and also full body surveillance—undergirds the understanding that medical care operates as an optional supplement to the required actions taken by patients. Similarly, the emphasis on the importance of family history further solidifies the understanding of breast cancer as an individualized disease (regardless of genetic composition), particularly when discussing women who do not have BRCA 1 and BRCA 2 gene mutations. For example, the Bring Your Brave campaign features the following biography:

Although Lisa’s genetic testing did not find a BRCA gene mutation, her family health history still puts her at a higher risk of getting breast and ovarian cancer at a young age. This is because the negative test result only shows that a BRCA gene mutation is *not* the cause of the increased prevalence of cancer within her family. It does not explain what *is* causing the increased breast and ovarian cancer risk in her family, such as a different type of genetic mutation. To address this risk, Lisa continues to take her doctor’s advice about breast cancer screenings and exercises regularly. (CDCBreastCancer, 2016c)

As with the previous examples about the importance of monitoring a body at risk, this excerpt serves to underscore both the notion of the female body as a site for unknown and potentially unruly dangers (for example, any manner of genetic mutation not yet

discovered or tested for), as well as the understanding that medical expertise bolsters the personal initiative that women must take in managing their cancer risk(s).

This dual focus that positions women as both self-advocates (ostensibly working against flaws with their providers or care) and as patients working under the expertise of medical providers ultimately functions to assert the primacy of patient agency by reinforcing the understanding that the medical establishment operates at the behest of patients. This attention on monitoring the body promotes agentic action while undermining the notion of the body as operating independently of modern medicine. This seemingly contradictory expectation placed on women is demonstrated by another Right to Know campaign poster which features a breast cancer survivor and her advice to other patients:

[June] tells us to ask for an accessible screening and not let the system decide what's best. Finding her cancer early allowed June to go on with her life. Screening allowed her to take control. (Right to Know, 2016a)

By emphasizing the shortcomings of the medical establishment (in this case, screenings for women with disabilities are often difficult or unsuccessful due to accessibility problems) while simultaneously instructing women to adapt to these shortcomings, this poster reassures women that they are always already in control, and thus should be unconcerned by these failings. Requiring women to identify and compensate for problems in the system, then, reinforces the understanding that women can take control of their situations and manage their bodies and/or disease through individual agency.

**Emotional care.** The rhetorical motif of the objectification of the self, as well as the responsibility for oneself (and to others), is carried over to emotional and psychological realms such that the acknowledgment of subjectivity functions to

underscore the expectation that women be autonomous in their health monitoring and management. The role of the medical establishment in emotional care is nearly nonexistent—rather than secondary or reactive—and operates to reinforce individual responsibility and agency by promoting self-initiative and resourcefulness as the primary resources for women. By defining optimal strategies for breast cancer patients to manage their disease, these campaigns construct the ideal ways for women to mobilize individual agency in these realms that are seemingly distinct from—yet inherently tied to—the body. As such, themes of resourcefulness and optimism are mobilized as integral components of self-care, particularly as they operate to bespeak the importance of women taking the literal and metaphorical lead regarding their health.

Successfully managing one's cancer diagnosis, per these campaigns, often requires adherence to, yet also control over, the dictums established by oncologists and related medical personnel. The role of medical intention, however, is overshadowed by the psychological fortitude that a patient must have in order to manage the physical impact of cancer treatment on the body, and thus, the importance of individual responsibility is normalized. For example, the following excerpt from an educational video about breast cancer treatments produced by the Beyond the Shock program addresses the strain placed on the body by certain treatments:

You need to be aware that more intense treatment methods will tax your body. During radiation therapy, it is essential to take care of yourself by getting extra rest and making good nutrition a priority. (Beyond the Shock, 2011b)

In addition to the actual directive for patients—rest and healthful eating—this excerpt demonstrates the fundamental, yet secondary, role that modern medicine plays in the cancer management process. While taking advantage of medical treatment is assumed as

a given, the management of that treatment and its side effects are entirely attributed to personal initiative and resourcefulness. By positioning individual agency as the natural—and singular—way to deal with the collateral damage inherent to most cancer treatments (in this case, fatigue), this campaign suggests resourcefulness on the part of patients is largely necessary as a response to, and accommodation of, medical intervention.

Maintaining a sense of resourcefulness—that is, successfully monitoring and managing one’s body, risk, and disease—in the face of a potential cancer diagnosis also undergirds one’s ability to create and/or sustain a positive outlook on both the diagnosis and the future (with or without cancer). Resourcefulness, then, is presented as empowering for patients by suggesting that acquiring knowledge about one’s risk or diagnosis operates to ensure—or at least work towards—a positive outcome in the future. This is seen in another participant biography featured in the Bring Your Brave campaign:

Jackie feels empowered by the roadmap she has created to manage her risk, and is hopeful for a bright future for herself and her 4-year-old daughter, Amelia.  
(CDCBreastCancer, 2016b)

In this excerpt, information illuminates the future for this previvor, thus suggesting that the power of knowing more about one’s risk and body reduces concern (but not likelihood of getting cancer). Even though the risk for getting breast cancer remains stable, the knowledge of this likelihood removes fear of the unknown and replaces it with the hope that future actions will be available to fight cancer, thus functioning to assuage concerns in both the emotional and psychological realms. The importance of easing one’s mind with knowledge acquisition is reiterated by the Beyond the Shock program which highlights how agency fosters hope for the future by emphasizing the importance of staying informed:



Embarking on this journey requires you to not only be informed, but also to realize that you don't have to face this alone. Family, friends, and other breast cancer patients are your shield and safety net, carefully knit together to strengthen you. (Beyond the Shock, 2011a)

You will need to make careful decisions and plans regarding your condition, but there is no reason to give up on life and relationships. Many women with Stage 4 cancer discover strength of character and qualities of resilience they never knew they had before. Remember to rely on your supportive group of family and friends. With their care and support, as well as your personal motivation, you will be able invest wholeheartedly in the options at hand, making the most of life for you and your loved ones. (Beyond the Shock, 2011d)

As with the Bring Your Brave campaign, these excerpts reinforce the importance of patients taking action in the midst of—and sometimes without the support of—the medical establishment's predetermined methods for treating cancer. That is, educating oneself about cancer must operate in conjunction with the support systems inherent to cancer management in order to maintain the expected optimism encouraged amongst breast cancer patients.

Relatedly, the emphasis on emotional care and control—both personal and from/with others—highlights the individualized nature of fighting cancer. That is, the success of treatments and recuperation hinge largely on the support system put in place by the patient, rather than the efficacy of the treatment or the proficiency of the medical team. For example, the following excerpt from a Beyond the Shock video about the types and stages of cancer reinforces the importance of support systems:

Your responsibility, as discussed in Chapter 4, is to develop a support team, of family or friends, that will comfort and encourage you in this time. (Beyond the Shock, 2011c)

In this case, the main task for breast cancer patients is to develop ways to handle the taken-for-granted treatments that they will take part in, thus reinforcing the idea that modern medicine happens in the background of the lives of patients. The primacy with

which emotional control is treated here renders medical decision-making as secondary; making emotional choices about support, then, are a key purpose and a primary method for patients in managing their diagnoses and treatment plans.

Across some of the most prominent and accessible “official” breast cancer campaigns and initiatives, the discourse articulates the disease as entirely in the control of women who are or might be affected by it; individual agency is paramount, and science and medicine are simply resources of which a woman might avail herself. Individual agency is understood to encompass both information and physical care, as well as emotional support; and it is represented as both an obligation to oneself and to others. Notably, this articulation turns on and reinforces a gendered mind-body dualism that posits the female body as especially suspect and subject to vigilant surveillance.

### **Common Discourses**

Produced concurrently with—yet distinct from—official discourses about breast cancer, common discourses about the disease operate within and arise from contexts and materialities that are not necessarily accounted for in public health campaigns. The common always draws upon dominant/official discourses and unofficial/unacknowledged discourses that reflect cultural impulses, sensibilities, and imperatives. As discussed at length in Chapter I, even if and as they draw from official discourses, mainstream news media in the United States, as privately owned entities, must resonate with their audiences, and thus comprise a common discourse, one reflective of resonant cultural imperatives and sensibilities while not constituting vernacularity per se. These discourses are mobilized in the texts that I have consulted for analysis, specifically coverage of breast cancer in the following venues for the last 3 years: *The New York Times*, *USA*

*Today, Time, and People.* Whereas official discourses turn on a presumption, valorization, and mobilization of individual agency and control, superior even to science and medicine, common discourses, as apparent in mainstream news media, encourage collaboration between patients and providers, but ultimately deem it nonviable due to medical provider inadequacies. As such, these common discourses posit and privilege an individual whose agency is hampered, if not frozen, by medical contradiction and controversy, evincing an overarching motif of fatalism.

### **Bad Medicine**

Contrary to the intended message and outcome of public health campaigns about breast cancer, the medical establishment is drawn into common discourses in ways that question the abilities of modern medicine to diagnose and treat breast cancer. This suggests a stronger role for the medical establishment than in official discourses—that is, implying more of a partnership between the individual agent and medical providers—such that the failings of the medical establishment are more profound and punctuated in common discourses. Whereas official discourses about the disease position the medical establishment as secondary to individual agency and functioning at the behest of the patient, common discourses explicitly challenge the inner workings and intended outcomes of the medical establishment and position it as ultimately working against the needs and desires of breast cancer patients. This representation of a dysfunctional medical establishment is mobilized via an emphasis on the paradoxical primitiveness of medical science, the ineptitude of modern medicine, the potential for/ practices of corruption within the medical community, and the threat of new harms caused by breast cancer interventions.

**Primitive science.** In the wake of a decades-long war against cancer that hinges largely on advances in modern medicine, the medical establishment is held up as a fallible institution that has ultimately been unsuccessful in improving its approaches to treating breast cancer. Emphasizing the outmoded and/or unsuccessful nature of many diagnostic measures and treatments, the potential for overdiagnosis and overtreatment, and the negative outcomes associated with these related phenomena, these common discourses construct a motif of primitiveness that both implicates and absolves the medical establishment of responsibility for the lack of progress in creating more effective measures for dealing with this disease. That is, the status quo is understood as a continuance—rather than an evolution—of the antiquated (and often barbaric) treatments and imprecise diagnostic measures initially used to detect and treat breast cancer, thus further reinforcing the current state of breast cancer fighting measures and normalizing the impracticality of expecting/demanding better. The (poor) current state of the art is highlighted in an article in *The New York Times*:

For decades, the specter of women dying for lack of intervention has made aggressive treatment a given. (Hafner, 2015)

Alluding to the embedded nature of aggressive treatments as the standard operating procedure (though not necessarily the most successful or desirable), this article emphasizes the overall stagnation that shrouds breast cancer treatments, thus reinforcing the centrality of antiquated methods to breast cancer treatment. By consistently privileging aggressive approaches—despite the problems inherent to them—the medical establishment reinforces a reactive stance towards women’s health that is both normalized and normalizing, resulting in a reliance on antiquated methods that fails to take into account alternative approaches due to the fear of fatalities.

With aggressive treatment the norm for dealing with a cancer diagnosis, the processes of detecting the disease remain similarly entrenched and ineffective. As such, inquiries into the inner workings of the body and cancer are often rendered as guesswork for those trying to determine how to approach the disease. For example, in an article in *USA Today*, the disease and related screening processes are represented as nebulous and antiquated processes, rather than streamlined or even scientifically grounded:

Cancer screening is like searching for needles in a haystack. The needles are the women with breast cancer. The hay is the healthy population. [...] Cancer screening is a blunt tool. We have to screen everybody to save the few we can. The more screening, the more likely that women will have an adverse experience – a false positive, an unnecessary biopsy or even unnecessary treatment. (Etzioni & Oeffinger, 2015)

Cancer screening practices, in this case, are understood to be both misguided and ineffective, serving mainly as hopeful shots in the dark as opposed to sound and proactive measures in which the public should partake. When characterized as a “blunt tool” that will ultimately save the lives of relatively few patients, these processes more closely resemble the erroneous instruments of early efforts at medical treatment rather than the results of decades-long research that have come at the expense of thousands of lives and millions of dollars.

Drawing on the dichotomy of both accepting and challenging the status quo alluded to at the beginning of this section, news discourses frequently address the perceived barbarism of breast cancer treatments and question the steadfast acceptance of these primitive approaches to treating (and ostensibly healing) women’s bodies. The treatments that result from questioned detection measures are often framed as anachronistic—yet ultimately normalized—such that the perceived outdated ways of treating breast cancer are understood to be routine, rather than necessarily effective or

progressive. Drawing on primitive notions of barbarism and unruliness, multiple articles challenge the progress made in breast cancer treatments:

But what I hope that people realize is that we really don't have good prevention for breast cancer. When you have to cut off normal body parts to prevent a disease, that's really pretty barbaric when you think about it. (Parker-Pope & Belluck, 2013)

Visco says Jolie's story, in spite of her use of genetic testing, illustrates how little progress has been made against cancer. "We have invested billions of dollars in science and raising awareness, yet we have little more than disfiguring and barbaric options to offer women like Ms. Jolie." (Szabo, 2013b)

Highlighting the seemingly unusual practice of removing healthy body parts in the service of maintained or future health, both of these articles suggest that the narrative of medical progress—as traditionally signaled by the money spent on research and awareness—is misleading and ultimately useless when put in practice. That is, the funds spent on exploring alternative prevention measures and treatments are ultimately immaterial, and thus allude to the possibility of other influences that support primitive methods, despite the financial support available to find more optimal choices (discussed more below).

Finally, the general aura of ineffectiveness that undergirds primitive science is further articulated by the emphasis placed on the frequency of overtreatment and overdiagnosis, practices that amplify the harms associated with outmoded medicine. Often framed as being either the best possible solution under the circumstances or an ill-informed reaction, overtreatment and overdiagnosis are discursively constructed as existing on the margins of the fight against breast cancer, mobilized out of fear or exhaustion rather than utility. In addressing the recent spike of excessive diagnoses and treatments amongst breast cancer patients, news discourses about these issues invoke

notions of primitiveness as they examine how modern medicine unsuccessfully contends with cancer. When discussing high rates of unnecessary treatments, an article in *The New York Times* alludes to the primitive nature of detection measures and the uncertainty involved in diagnosing breast cancer:

“We would all love to avoid diagnosing and treating a breast cancer that doesn't need treatment,” Dr. Oeffinger said. “But we don't have the tools.” (Grady, 2015)

While this excerpt speaks to the dearth of effective measures for determining which cancers pose the greatest threats, it also mobilizes this notion of primitiveness in distinct ways such that it highlights the lack of options available to doctors. By calling into question the quality of the available options for treatment, this article suggests that the advances in modern medicine have ultimately created a double-bind for patients alike: that is, being proactive in learning one's risk and being diagnosed early are valorized, but seemingly pointless since no effective options are available to patients who do acquire this information.

Relatedly, the primitive nature of medical science extends to standard screening and prevention measures, mainly mammography. While a point of contention in the medical community, mammograms as a primary means of detecting cancer remain at the forefront of discourses about the disease. The attendant shortcomings involved with this form of screening—similar to the concerns involved with other tests—result in overtreatment and overdiagnosis being constructed as natural by-products of an imperfect tool and system. The limited utility of screening procedures in the face of unnecessary procedures and potentially ineffective diagnoses is addressed in an article in *USA Today*:

Beyond “false positive” results – which can lead women to undergo additional tests and painful biopsies – mammograms can lead to “overdiagnosis,” causing women to be treated unnecessarily for slow-growing cancers that would have

never become life-threatening. “We're moving to an era where people are recognizing the limitations of screening tests,” said physician Nancy Keating, who co-wrote an accompanying editorial in JAMA. (Szabo, 2015b)

By highlighting the limitations of the available means of detection, this article demonstrates the understanding that the inadequacies and outdated nature of medical science are known, but ultimately inevitable. Acknowledging the shortcomings in detection and treatment merely serves to highlight the normality of their presence, rather than challenge the status quo. As such, while the primitive nature of breast cancer care is illuminated, no alternatives currently exist. Similarly, the following excerpt from *USA Today* highlights this approach to overtreatment and overdiagnosis that underscores the primitiveness of the primary means of detecting cancer:

While we believe its [mammography] harms, particularly overdiagnosis, are often exaggerated, we acknowledge that mammography is not a simple test. If we want to save screening, we have to acknowledge its potential downside. Screening is not a magic magnet, even though we can't help wishing it were. (Etzioni & Oeffinger, 2015)

Despite challenging the perceived prevalence of overdiagnosis (and ostensibly overtreatment), this article ultimately reinforces the taken-for-granted notion that the current state of breast cancer detection—while certainly less than ideal—is as good as it is going to get (at least for the present). Primitive science, then, is again reaffirmed as the norm because of the lack of innovation and effective alternatives; as such, any protestations against it are merely whimsical desires that have no basis in reality (that is, wanting mammography to be more accurate is equated with magic).

**Inept medical establishment.** Attendant to the apparent shortcomings in the means and ends of modern medicine is skepticism about the efficacy of medical providers as the wielders of primitive science. Frequently implicated in these discourses



is the unsatisfactory nature of the medical establishment's success in preventing, detecting, and treating breast cancer, particularly as it pertains to the contradictions that are inherent to these ultimately subjective processes. Despite the aura of objectivity that shrouds medical science, these discourses illuminate how confusion amongst both patients and providers regarding optimal courses of action is a systemic problem in the medical establishment. Highlighting the ineptitude of this establishment is an emphasis on revelation, or pulling back the curtain on what medical providers actually can do and know about cancer. For example, articles from *USA Today* highlight the chasm between scientific inquiry and the current state of affairs:

Scientists don't even know what causes most breast cancers. (Szabo, 2013c)

Science often gives us information we do not know what to do with. (Visco, 2015b)

In these instances, scientists—and by extension, medical practitioners—are presented as being in a double-mind of their own making: they have produced a lot of information, but generally not the correct or useable information that would assist in the detection, prevention, and treatment of breast cancer, and thus must now make sense of both the known and unknown. Articles in *Time* and *The New York Times* reaffirm the importance of being able to mobilize information—and specifically, breast cancer diagnoses—rather than just continually discover more:

“It's not the ‘finding more’ that we need to work on. It's what are we going to do with the more that we find?” (O'Connor, 2015)

“When we talk about watching and waiting with D.C.I.S. [ductal carcinoma in situ], the question is, ‘How do we know it's just D.C.I.S.?’ The answer is that we don't.” (Hafner, 2015)

As these excerpts allude to, the exploration of the body inevitably uncovers maladies and

irregularities, yet modern medicine is generally not equipped to handle or act on these findings, thus, the achievement of exploring the body has raised more questions than provided answers. Additionally, these combined excerpts also work to undermine both the means and ends of the medical establishment by calling into question the utility of what has been accomplished and what is still being researched, thus suggesting that the breast cancer detection/treatment quagmire is essentially an infinite feedback loop of unusable information.

Drawing on notions of primitive science, these discourses frequently reify the ineptitude of modern medicine when discussing physicians—as the users of blunt tools—and representing them as the progenitors and purveyors of this confusion and ineffectiveness. For example, in an article about former *Good Morning America* cohost Joan Lunden’s breast cancer diagnosis, Lunden highlights the immobility that arises from the expert opinions of physicians:

Despite her having access to top breast cancer experts, “there’s such a disparity in the advice people give you about which path to take,” she [Lunden] says. “You go to three oncologists, and they all tell you to treat it in a different way. That’s a really scary position to be put in. It can paralyze someone.” (Strohm, 2014)

The negative impact that stems from the lack of agreement about optimal courses of actions for breast cancer patients to take undermines the importance of this knowledge. That is, the utility of expert opinion is hindered by contradiction such that, once again, more knowledge is presented as being the source of—rather than solutions to—problems. Disagreement among medical practitioners is further highlighted in *USA Today*:

Pathologists disagree more than many realize, particularly about precancerous lesions, according to a study in March in the *Journal of the American Medical Association*. (Oldenburg & Puente, 2015)

By illuminating the disparity between the reputation and reality of the medical

establishment—and specifically pathologists, in this case—this excerpt suggests that the state of medical opinion—as well as the definition of cancer—is inherently determined by the fallibility of human subjectivity. As such, even the information that is perceived to be understood and useful is ultimately called into question by disagreements among those who are in control.

This internal uncertainty and inconsistency in the medical establishment extends to the best courses of action that physicians can recommend based on their (apparently) limited knowledge about the progression of cancer. Concerns over the ability to treat cancer effectively imply that the entire system—from detection and diagnosis, to treatment and recurrence prevention—is ultimately not operating in service to women, but rather at the expense of women. In this case, then, allusions to the harmful, ineffective, and temporary nature of many breast cancer treatments suggest that shortsightedness is at the helm of these cancer care innovations. For example, an article in *USA Today* highlights how the immediate efforts of the medical establishment are reactionary rather than reasonable:

Breast cancer advocates – tired of seeing women beaten down and burned by toxic treatments – are eager for a game-changer. (Szabo, 2013c)

That means those patients could have been subjected to unnecessary procedures, such as surgery, chemotherapy and radiation, which could actually do more harm than good, given their complications. (Park, 2014)

In these cases, the shortsightedness of physicians is apprehended as being deleterious to both women who need treatment and those who do not, as they are treated as one-and-the-same by physicians who cannot distinguish between the two. Positioning physicians as reactive rather than deliberative suggests that they approach patient care as a one-size-fit-all treatment situation, despite the apparent short- and long-term harms associated with

the treatments that encompass this approach. Relatedly, the inability to decipher which cancers pose a threat and which do not also plagues discussions about the efficacy of physician decision-making:

Because doctors can't be certain which breast cancers will prove deadly, they typically recommend treating all of them. (Szabo, 2015a)

Some cancers don't progress, some may even disappear on their own, and others may grow so slowly they would not become a problem during the remaining years of life. But doctors cannot tell with certainty which cancers are safe to leave untreated. (Brody, 2014b)

By evidencing the general lack of knowledge that pervades the medical establishment, these articles in *USA Today* and *The New York Times* suggest that cancer is frequently regarded as generic and standardized, and thus physicians treat most (if not all) cancers in the same ways. As this approach aligns with a lack of knowledge and more concern for the present (that is, treat now and deal with the consequences later), it represents physicians as ultimately operating in the best interest of time, rather than the patients themselves.

Further enhancing the perspective that doctors are failing to fulfill their responsibility to treat patients effectively and with minimal harm is the understanding that the information made available to physicians is not actually useable and is at least harmful. Alluding to the problems inherent to a mass of unusable information, the following examples attend to the obscured role that these tests play in screening and treating patients:

More challenging for doctors trying to guide patients through their choices is the fact that many cancer-screening tests, especially nongenetic ones, do not yield clear treatment options. (Park, 2013)

In the past, overdiagnosis was thought to apply mainly to ductal carcinoma in situ, or D.C.I.S., a breast growth that may or may not turn cancerous. Now, researchers

think that invasive cancers are also being overdiagnosed and overtreated by mammography. (Grady, 2014)

As both of these excerpts demonstrate, the fallibility of physicians as decision makers is rendered a primary threat for women, especially those who choose to partake in breast cancer screening. In the former example, enhanced detection measures that are available to physicians are presented as informative, rather than directive, suggesting that physicians produce more information than they can effectively mobilize. Similarly, in the latter example, the common detection tool frequently utilized by physicians—mammography—is presented as an accompaniment to the inadequate performances of physicians. That is, the inability to interpret the wealth of information provided by screening technologies positions physicians as being paradoxically blinded such that the more access they have to the inner workings of a woman's body, the less they can help it.

Finally, the primacy placed on specialized care and personalized medicine is articulated as another instance in which the ineptitude of the medical establishment hinders patient care through stymied attempts at asserting patient agency. In this context, patients are expected to operate in the realm of personalized medicine—a privileged and idealized notion of successful medical interventions designed for specific patients that hinge on scientific advancements—despite the overall inability of the medical establishment to actualize and mobilize such interventions. The integration of specific, individual information from patients that charts risk—garnered through genomic and other testing, as well as family histories—is presented as ambiguous, confusing, and even controversial. For example, articles in *Time* and *The New York Times* attend to the spate of individualized testing and treatment currently available or conceptualized for the future:

Thanks to advances in genomic testing and deeper insights into the biology of different kinds of breast cancer, doctors are learning that the one-size-fits-all approach isn't working. They're also learning that every woman brings with her a unique profile of biological risk—as well as a unique appetite for risk. That means that while some women require urgent and aggressive treatment, there are many who can slow down and take a more sparing approach. (O'Connor, 2015)

“Treatment today is getting much more individualized,” Dr. Hudis said. Depending on the molecular nature of a woman's tumor, postoperative hormonal or other drug treatments are routinely prescribed to prevent or delay a recurrence of disease. (Brody, 2014a)

Experts say they aren't sure how these conflicting recommendations will affect death rates, but they expect continuing advances in treatment. Susan Brown of Susan G. Komen Foundation, the breast cancer organization, says there's a trend toward more targeted, individualized therapies, and treatments will get only more personalized in the future as scientists learn more about the biology of tumors. (Ungar, 2015)

Obfuscating the multitude of barriers to system-wide implementation of individualized treatment, these articles mollify concerns that women will forever be victims of an ineffective system by suggesting that once ineffective treatments will soon be replaced by preferable alternatives. While this transition to personalized medicine is presented as desirable, this attention to the promises of future interventions ultimately underscores the current inability of (many) medical practitioners to incorporate these technologies and findings, thus the emphasis on the revelatory departure from a one-size-fits-all approach to care.

**Corrupt establishment.** Underscoring the primitive nature of the means and ends of the medical establishment's approach to treating breast cancer is an implicit understanding that these means and ends are extrinsically motivated on the part of medical providers. As such, the methods and goals of medical providers and others involved with the disease (for example, lobbyists, awareness organizations, insurance companies, etc.) are called into question for the seemingly nefarious motives that

undergird the decisions made by these entities. A corrupt medical establishment, then, reinforces its broader characterization as dysfunctional since it purportedly hinges on factors external to patient care and betterment. Corruption is mobilized in these discourses through an emphasis on financial gain and influence from external entities.

Concerns over financial motives driving decision making about medical care center primarily on the cost-cutting and profit-seeking practices commonly associated with for-profit organizations, thus representing cancer care as a self-serving business rather than a patient-centered venture. Decisions that are called into question by these discourses—for example, changing the guidelines for recommended mammograms—are routinely imbricated with the possible financial motive that would undergird such choices, particularly in the event that the medical establishment is divorced from the benevolence that is often culturally tethered to the medical profession. For example, when discussing the adjusted recommendations for annual mammograms in the United States, *The New York Times* highlights the financial interests seemingly inherent to this decision:

At the same time, we observe that in a panel that included an economist and public health experts, there was potential for bias the other way – in favor of cutting costs over saving lives. (Port, Sonnenblick, & Drossman, 2015)

By explicitly challenging the presence of figures most likely to have financial interests at the forefront of their expert contributions (that is, an economist), this article highlights the threats posed by bias (read: systemic corruption) that puts primacy on turning a profit. Further drawing on concerns about the possibility of collusion amongst those involved in the implementation and practice of breast cancer detection and treatment processes, the following article from *USA Today* discusses the little-followed recommendations for

shorter radiation treatments:

“How much evidence does the medical community need before it changes practice?” says Visco, who notes that doctors may make more money from longer treatment courses. “As patient advocates, we don’t want to believe this is financially motivated but find it difficult to understand what else could be the barrier.” (Szabo, 2014)

By citing the financial incentive for physicians to ignore evidence of a more convenient and less harmful radiation schedule for patients, this article centers concerns about corruption within doctors as a product of the system. That is, current practices are well-entrenched in the medical establishment such that changes on the parts of individual doctors would be examples of going rogue, rather than systemic change, thus further reifying the understanding that the system as a whole is flawed and operates against the best interests of patients. A related—and final—example of financially motivated corruption attends to the lack of legitimacy granted to alternate treatments not produced by modern pharmaceutical trials. An article about the potential for aspirin to prevent breast cancer addresses this invalidation:

It’s not hard to see why: Clinical trials are typically conducted on drugs developed by labs seeking huge profits. No one stands to make money off aspirin, which has been a generic drug since the Treaty of Versailles in 1919, and which costs less than \$6 for a year’s supply. (Holmes & Chen, 2014)

Noting the limited financial gain to be made from establishing a causal link between aspirin and reduced risk of breast cancer, this article reinforces the notion of the system as an enterprise motivated by profit rather than patient wellness. Thus, a corrupt medical establishment does not inhere solely in the decisions of physicians but rather in the firmly embedded normalized and normalizing practices that account for why financial gain would be a commonsense response to cancer treatment innovations.

Based on this perception of the medical establishment as a whole as self-serving,



the credibility and benevolence that are culturally ascribed to the medical establishment are further challenged through the presence and perceived influence of entities external to patients and providers. Whereas profit motives are understood to be central to the medical establishment, the presence of additional voices in the cancer care conversation are represented as being just as harmful to patient outcomes. For example, *Time* attends to the influence wielded by nonmedical professionals in the process and practice of detection and treatment options:

MEDICINE IS SLOW TO MOVE, and that's especially true with breast cancer. Doctors are up against not only new data but also an accumulated mass of public opinion seeded by policymakers and advocacy groups with strong positions on how best to screen for and treat breast cancer. [all caps in original] (O'Connor, 2015)

By addressing the impact of public opinion—that is, the desires of the population writ large—on the decisions of doctors and ultimately the progress of medical innovation, this article positions public opinion as ineffectual interference that is fueled by self-serving groups. As such, individual doctors receive clemency relative to the medical establishment, since the former are represented as beleaguered and downtrodden by the process of trying to appease the desires of interested parties, while the latter is portrayed as adding to this discomfiture in the form of data. Relatedly, a *USA Today* article singles out breast cancer as distinct from—yet certainly related to—the medical establishment since it has become a business outside of the disease itself (for example, pink products as disease awareness and support):

Since my diagnosis, breast cancer has become big business. The popular press took on breast cancer as a cause and supplanted science as the main source of information. [...]. It is only going to get worse. Science often gives us information we do not know what to do with. Then technology and marketing step in. (Visco, 2015a)

In addition to alluding to the primitiveness of modern medical approaches to breast cancer, this excerpt also operates to position the aura around the disease as a for-profit enterprise. Capitalizing on this ineptitude (that is, the inability to mobilize the mass of data available about the disease), profit-seeking entities are positioned as having primary control over how the disease is represented and perceived on the public agenda. The medical establishment—as subject to the designs of others—is portrayed as being ultimately ineffective in controlling the narrative about breast cancer, often to the detriment of medical professionals and patients. Thus, how the medical establishment mobilizes information about the disease is rendered negligible since it has ultimately enabled this corruption due to its mishandling of data.

**Threat and creation of harm.** Integral to the notion of bad medicine is the impending threat of new and unwarranted harms caused by the shortcomings of the medical establishment. In addition to the harms created by those procedures deemed necessary for diagnosing and treating preexisting breast cancer (for example, pain and disfigurement from mastectomies), the medical establishment is implicated in the creation of new and unnecessary harms that result from primitive science and inept methods. As such, patients are positioned as victims to a modern-day *pharmakon*: breast cancer treatments operate as both remedy and poison, attending to problems while simultaneously creating new ones. The risks inherent to breast cancer treatment, then, extend beyond known side effects and cast a specter on the future health of patients, especially as this future may be delimited by unknown ramifications of treatment. For example, the following excerpts from articles in *The New York Times* and *USA Today* highlight the threats posed by radiation therapy:

Women treated with radiation for breast cancer face an increased risk of heart attacks and premature death, even 20 years after the end of treatment, a study shows. The study is the latest to document the serious long-term health problems faced by cancer survivors. Although improved treatments allow more people today to survive their disease, these toxic therapies also lead many to suffer chronic health problems. (Szabo, 2013a)

Although doctors try to spare the heart, it still gets some of the dose, especially when the left breast is treated. Radiation can damage the linings of blood vessels and scar the heart muscle. (Szabo, 2013a)

In these instances, women's bodies are treated as collateral damage in the process of treating breast cancer, thus placing them in the position of having to accept one risk in order to eliminate another. By attending to the tertiary outcomes of cancer treatment—in this case, heart problems from radiation therapy—these articles highlight not only the ultimate lack of optimal choices for women, but also the ineffective methods for administering treatment.

New risks also result from the confusion about breast cancer that underscores both the lack of knowledge about the disease and the inability of physicians to mobilize what is known about it. A primary example of this confusion is the contested position of mammography as the mainstay in breast cancer detection and prevention. Combining both the dearth of usable information and the contradictions amongst medical providers, discourses about mammography highlight the threats inherent to this screening tool. For example, the following two excerpts from articles in *The New York Times* acknowledge the short- and long-term problems attributed to this technology:

The changes reflect increasing evidence that mammography is imperfect, that it is less useful in younger women, and that it has serious drawbacks, like false-positive results that lead to additional testing, including biopsies. (Grady, 2015)

One of the drawbacks of screening is false positives: over 10 years, a woman receiving an annual mammogram has a 61% chance of getting such erroneous results. Another is mounting evidence that aggressive treatment of some early-

stage cancers is unnecessary and can have lifelong side effects. (Sifferlin, 2015)

As these articles suggest, the standardized role of mammography in breast cancer screening extends to the practice of routinely overdiagnosing and overtreating women, resulting in a tautological system of looking for and finding and/or creating cancer. By creating new problems that cannot be adequately handled by the medical establishment, breast cancer screening positions women in a consistent state of unease due to the omnipresent threats posed by both cancer and the search for it.

A final instantiation of new harms posed by breast cancer screening and cancer care calls into question the efficacy of prevention and treatment medications. As part of the arsenal of cancer treatments, chemotherapy is understood to have side effects for patients (for example, hair loss from certain cocktails and nausea from treatment). While the immediate side effects are well known, the lesser known and long-term material impacts of this treatment are highlighted as being unwarranted harms added onto the preexisting concerns for those received chemotherapy. For example, an article in *USA Today* addresses the shortcomings of chemotherapy drugs and the measures patients must take to compensate for the damage done to the body in the process of trying to heal it:

Certain chemotherapy drugs also can cause heart failure [...]. Lastly, chemo often throws women into early menopause, which causes many breast cancer survivors to gain weight [...]. That puts further stress on the heart. Because cancer treatment can damage the heart and blood vessels in so many ways, leading a healthy life -- with a good diet, lots of exercise and no smoking -- is crucial, Smith says. (Szabo, 2013a)

In this instance, women are not only positioned as being plagued by the alleged cure for their malady, but also expected to anticipate and accommodate the new problems associated with their treatment. This allusion to the power of patient agency identifies the ultimate lack of control that patients have in the face of new and unexpected threats;

articulating the steps patients can—and should—take to prevent future problems caused by chemotherapy highlights the deficit created by breast cancer treatments. In this way, women must take action to achieve and maintain baseline, rather than optimal, health just to manage their risk of deterioration caused by those measures intended to restore health. Similarly, preventative cancer medications are questioned for their utility in preventing one cancer while simultaneously increasing the risk of developing another (among other issues). Addressing these concerns, an article in *The New York Times* challenges the perceived value of these medications in relation to the threats caused by them:

Many healthy women, even if they are at increased risk, refuse the drugs, asking why they should take pills to lower the odds of a disease they may never get anyway, especially when the drugs can have dangerous or unpleasant side effects. Besides increasing the risk of blood clots and strokes, the drugs can also cause hot flashes and vaginal problems like dryness and pain that can damage a woman's sex life. In addition, tamoxifen can lead to cataracts and uterine cancer. (Grady, 2013)

Diverging significantly from discussions about chemotherapy drugs—which cause problems while treating preexisting cancer—this example attends to the invited trouble that patients take on when partaking in prevention measures. By highlighting the multitude of new harms that await patients who are proactive in breast cancer prevention, this article suggests that women must negotiate the potential harms against the unknown benefits from these drugs. That is, the benefits are likely to be unknown—the lack of a cancer diagnosis is not proof the medication worked—yet the harms are known, thus requiring women to select which threat they prefer.

The four prongs that undergird the notion of bad medicine—primitiveness, ineptitude, corruption, and new harm—result in an overarching motif of fatalism that underscores a perceived lack of hope, clarity, and prospect for recovery on the part of

patients. These common discourses challenge the official discourse's uncomplicated valorization of personal agency on the part of patients; despite striving to situate control within patients, these common discourses articulate a medical establishment that is unable to help and empower patients, and often operates as a hindrance. The role of the patient in this situation, then, is expected to be agentic and have the ability to adapt to and compensate for ineffective care, but is ultimately thwarted in those efforts by an ineffective medical establishment. As such, these discourses illuminate that what patients ought to be able to do in regard to their health does not align with what they are able to do in practice, thus further reaffirming the fatalistic perspective on the state of modern medical approaches to breast cancer.

### **Trench Warfare**

Emerging in these common discourses is an ancillary discourse that prompts women to actively see the medical establishment as oppositional to their interests and to take matters into their own hands. Seemingly in response to the four prongs of “bad medicine”—primitive tools, physician ineptitude, corruption, and new harm—this discourse moves beyond the perception of the medical establishment as a lacking or failed partner and describes it as actively oppositional to women's health and interests, but necessary to navigate nonetheless. The helplessness of the patient that the collective “bad medicine” discourse arguably prompts still relies upon fatalism, but in a reactive “last resort” or “no other option” way. That is, it is mobilized as women being forced to take over their health and treatment into their own hands in an attempt to recoup agency that is described as obviated in the bad medicine discourse; this is manifest in two ways: via intuition and actual direction.

Intuition is advanced as the primary touchstone in this ancillary discourse in the absence of effective or credible guidance from the medical establishment. Women are encouraged to trust their instincts in determining what resources to assess and/or utilize. For example, the following excerpts emphasize the importance of instinctual responses to a breast cancer diagnosis:

As with Jolie, Wilson's candor drew praise. "Rita Wilson has become the poster child for both second opinions and trusting your own instincts with regards to your body..." (Oldenburg & Puente, 2015)

[Rita Wilson] "For me, this is about telling people, 'you can get a second opinion – your insurance will pay for it, even Obamacare, God bless it, will pay for it,'" she said. "It's so easy to say, 'I'm just being paranoid,' but you should trust your gut." (Lyll, 2015)

Though it was the most aggressive surgery option, Robach felt strongly about her decision. (Less invasive approaches, including lumpectomy, were also discussed.) Her "gut feeling" to undergo the bilateral mastectomy is a decision the mother of two is grateful she made every day because a second, undetected malignancy was discovered during the operation. (Strohm, 2015)

Robach made the decision to have the most aggressive surgery she could to treat her breast cancer: a double mastectomy. "I just had a visceral, immediate gut feeling that this is what I wanted to do," says Robach. (Cotliar, 2013)

Implied in these examples is the presence of bad medicine: first, ineffective medical care received by Wilson—thus necessitating second opinions to verify the work of physicians—and second, primitive options for Robach in dealing with her cancer diagnosis—hence her double mastectomy being highlighted as the most aggressive surgical option available to her. Importantly, these articulations of the medical establishment's shortcomings are assuaged by the healing capacity of women's intuition in so far as it guides them to optimal choices for their situations. Not only are these demonstrations of instinct portrayed as authentic and authoritative—that is, Wilson is praised for her transparency and determination, while Robach is portrayed as the driving

force behind her decision—but they are also represented as the natural response to bad medicine because gut reactions and knowing one’s body are the purview of the patient. Thus, by operating within an overarching discourse of fatalism that reifies patients as victims of both bad medicine and cancer, these excerpts articulate instinct as an avenue to better or more satisfactory care.

Reactive agency is also described in this discourse as material and operational. That is, as clear, specific directives issues by patients to providers—arguably, a “muscular” and conventionally agentic complement to the “female intuition” articulated as the first line of defense. For example, articles in *The New York Times* attend to the voices of patients in shaping medical decisions and healthcare trends:

A new generation of women want doctors to take a more aggressive approach, and more and more are asking that even healthy breasts be removed to ward off cancer before it can strike. (Parker-Pope, 2013)

“Defaulting to patient preference in the face of uncertainty has become the moral high ground,” Dr. Rosenbaum wrote. “But it is as much our job to figure out how to best help our patients lead healthier lives as it is to honor their preferences.” (Brody, 2014b)

“There’s no right or wrong decision, as long as patients are well-informed and choose what is best for them,” said Dr. Jennifer K. Litton, a surgical oncologist at M.D. Anderson Cancer Center in Houston. “The old days of paternalistic medicine are gone.” (Brody, 2014a)

As indicated in the *People* article about Robach’s double mastectomy and demonstrated here, aggressive self-advocacy about preferred treatments is represented as a response to inept or unsatisfactory care, particularly as those shortcomings are mobilized on the part of younger patients. This ancillary discourse, as noted, is nonetheless situated in a broader common frame of fatalism as regards breast cancer treatment. It mobilizes that frame differently, though, in its attempt to reassert patient agency insofar as it replaces



the helpless, victimized patient of “bad medicine,” as a failed partner, with an oppositional construct that situates the medical establishment as an obstacle to be overcome.

### **Summary**

This inquiry into the rhetorical construction of medicine and patient agency in public health campaigns and news coverage about breast cancer suggests that, while the patient and the medical establishment are centrally figured into both of these discourses, there are significant differences in how they are ultimately constructed. While both sets of discourses valorize patient agency, the primary divergence between these official and common discourses about breast cancer resides in the efficacy of the medical establishment. Whereas the former takes for granted the effectiveness of physicians and medical science in the fight against breast cancer, the latter apprehends the establishment as both incompetent and impotent, at best, and downright dangerous, at worst, suggesting that the limited power it does have to attend to women’s health is stymied by a multitude of shortcomings. Furthermore, official discourses view the medical establishment as benevolent, cooperative, and helpful, if secondary, whereas common discourses view it as inept primitive, corrupt, and a failed partner. As such, women’s agency is defined and qualified by the fatalism created and bolstered by bad medicine, resulting in an expectation for patients to adapt to and compensate for this incompetence.

### CHAPTER III

#### TO INVISIBILITY AND BEYOND: THE NEBULOUS DISCURSIVE NATURE OF BLADDER CANCER

Known as “the invisible cancer,” bladder cancer is situated within a constellation of juxtapositions that render this reputation both troubling and surprising: it is one of the most common cancers, yet perceived to be the least common by the public (Jensen et al., 2014); it is the most expensive cancer to treat, yet it is one of the least funded (Lotan et al., 2009); and approximately 77,000 new cases will be diagnosed in the United States in 2016, yet it is one of the most underrepresented cancers in the news and has no dedicated public health campaign in the United States (American Cancer Society, 2016; Jensen, Moriarty, Hurley, & Stryker, 2010). Considering these factors, the conspicuous absence of bladder cancer from the public agenda calls into question what information—if any—about the disease resonates with the public, as well as how the disease is constructed and negotiated by official health organizations and patient advocacy groups.

In this chapter, I examine how, in the absence of a national-level public health campaign, bladder cancer organizations and patient advocacy groups discuss the disease, paying particular attention to how preventative, diagnostic, and treatment processes are rhetorically constructed. Additionally, I analyze how mainstream news discourses about the disease converge and/or diverge with these official dictates about bladder cancer to see which ideas potentially gain traction in popular media outlets. The importance of this

inquiry is located within its potential to see how a largely ignored—yet prevalent and threatening—disease is discussed in both health and news spheres, and how these articulations of the disease potentially indicate ways to enhance care and improve awareness about it in the medical community and the general public.

### **Official Discourses**

Like public health campaigns, health organizations and related patient-centered online resources provide consumers with prevention, diagnostic, and treatment information about prevalent health concerns. Also similar to public health campaigns is the fact that this information is rhetorical in nature: it operates in relation to cultural perspectives and discourses about how we tend to understand health conditions and those affected by them, as well as the potential causes and solutions for them. These resources, then, prove to be especially vital when they are about health issues or conditions that—for whatever reason—fail to garner the funding or attention for an official awareness campaign. As such, these official discourses provide an authoritative lens through which consumers can learn more about those health concerns that do not occupy a consistent position on the public agenda—in this case, bladder cancer.

Perhaps not surprisingly, the “invisible cancer” is largely absent from domestic online resources about cancer.<sup>3</sup> Thus, the discourses selected for inclusion here—though not associated with any governmental and public initiatives to raise awareness about the profile of bladder cancer in the United States—were identified due to their received credibility and authority on the subject, as well as their availability. First, the American

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<sup>3</sup> Public health campaigns about bladder cancer exist in Canada and the UK.

Cancer Society (ACS) is a leading authority on cancer and thus the ACS website serves as a general resource for all cancers. Specific to bladder cancer—and included here for study—is the ACS’s detailed bladder cancer guide that consolidates all of the ACS’s content about the disease into one document. Second, the Bladder Cancer Advocacy Network (BCAN) serves as the only national non-profit advocacy organization in the United States about the disease and its website provides information, patient resources, and research updates. Finally, the nonprofit American Bladder Cancer Society (ABCS) website—started and designed by bladder cancer survivors—features help guides and other patient resources designed to improve the communication between patients and their providers.

These online resources about bladder cancer are important to study because they are the official channels through which most (if not all) information pertaining to the disease is made available to the public. The limited availability of bladder cancer resources and awareness initiatives also renders these websites key texts for study, especially since they present a range of resources likely searched for by interested parties: scientific perspectives on the disease and research developments, as well as patient-centered guides and contact information for providers, clinical trials, and the like. When analyzed together, these official discourses position bladder cancer as an unknown—and even sometimes *unknowable*—disease that mystifies patients and providers alike. As relevant to providers, bladder cancer’s mystique is secured in the official discourse’s endorsement of medical *teams* rather than individual providers, who are concomitantly articulated as unable to decipher the condition on their own. It is patients, however, who are centered in this discourse, as seekers on a perpetual, directionless quest.

## The Unknown and Unknowable Cancer

Bladder cancer's status as essentially invisible across all sectors in the US—for example, funding, awareness, news coverage, and the like—is reflected in these online resources about the disease, primarily in the articulation of the disease as ambiguous—precisely, as deceptive and mysterious. Patient agency is encouraged, then, in the context of a quest, with no definitive object or end.

**Deception.** The standard imperatives of health and patient advocacy organizations—to highlight, inform, and empower—are mobilized in these discourses in ways that position the disease as inherently duplicitous. This deception is frequently mobilized via attention to bladder cancer masquerading as other health issues, these related health issues presenting bladder cancer symptoms, and an overall sense of wellness that obfuscates the presence or threat of the disease.

The duplicity that shrouds bladder cancer is underscored by the understanding that the disease frequently masquerades as other less severe health issues, and thus often goes unnoticed or is dismissed altogether. Symptoms, then, are represented as hiding in plain sight due to their ordinary and nonthreatening nature (e.g., lack of pain). For example, the following excerpts highlight the masquerading nature of bladder cancer:

Two features that tend to mask the severity of the gross hematuria and may influence patients to postpone seeking immediate medical care are 1) the bleeding may be occasional and short-lived; and 2) there is likely to be no pain associated with the bleeding. (Bladder Cancer Advocacy Network - BCAN, 2016e)

Bladder cancer symptoms may be identical to those of a bladder infection and the two problems may occur together. If symptoms do not disappear after treatment with antibiotics, insist upon further evaluation to determine whether bladder cancer is present. (Bladder Cancer Advocacy Network - BCAN, 2016g)

Bladder cancer survivors report that they may have had all, some or none of the above bladder cancer symptoms. Remember that while these are bladder cancer

symptoms they can be signs of other conditions. (American Bladder Cancer Society, 2016c)

Attending to the commonplace nature of bladder cancer symptoms, the first two examples suggest that the disease hides behind issues that fail to incite fear or significant concern in those experiencing the symptoms. Specifically, the second example highlights how more common health issues are given primacy (e.g., bladder infections) over the possibility of bladder cancer, thus rendering the disease as a slim possibility in comparison to those issues that are considered to be more likely to occur. Similarly, the final example alludes to the multitude of possibilities that exist in regard to bladder cancer symptoms such that the masquerade may point patients and physicians in a variety of wrong directions. One such direction that is frequently articulated is that which is specific to women and indeed considered far more likely than cancer: gynecological processes or problems. The following examples reinforce the representation of the disease as effectively hiding or evading detection:

Many women ignore the most basic symptom—blood in the urine—which they may associate with menstruation or menopause and delay reporting this symptom to their doctors. Even after reporting the problem to their doctors, blood in the urine may be initially misdiagnosed as a symptom as post-menopausal bleeding, simple cystitis or as a urinary tract infection. (Bladder Cancer Advocacy Network - BCAN, 2016g)

Women often have delayed diagnosis due to bladder cancer being mistaken for common gynecological problems. (American Bladder Cancer Society, 2016b)

I never had any signs or symptoms that would have raised a red flag. In hindsight, I had a history of bladder infections, kidney stones, some urgency, and some blood in my urine, which I assumed was just menstrual blood. (American Bladder Cancer Society, 2016e)

I had been having some symptoms such as pain and dark colored urine for several months, but I thought they were connected to menopause. (Bladder Cancer Advocacy Network - BCAN, 2016a)

By imbricating bladder cancer symptoms with those attendant to menstruation and menopause, these examples reaffirm the understanding that the disease not only evades notice and investigation, but that it perfectly aligns with those phenomena that women are always already primed to expect. As such, these discourses suggest that the disease effectively masks itself in ways that render concern about cancer to be misguided at best and alarmist at worst (a particularly salient situation for women whose credibility to speak up about their health concerns is at stake in these discourses).

Inversely, bladder cancer is equally hard to detect and comprehend due to the related health problems that mimic the disease and its few symptoms (e.g., blood in the urine). Whereas bladder cancer is often understood to be masquerading as other issues, other issues are also implicated as portraying themselves to be bladder cancer, such that detection measures seem not only challenging but ultimately unnecessary. As the following excerpts demonstrate, false alarms can be triggered due to the mimicry of other conditions:

Blood in the urine does not always mean you have bladder cancer. More often it is caused by other things like an infection, benign (non-cancerous) tumors, stones in the kidney or bladder, or other benign kidney diseases. But it's important to have it checked by a doctor so the cause can be found. (American Cancer Society, 2016c)

However, blood in the urine does not necessarily mean a diagnosis of bladder cancer. Infections, kidney stones as well as aspirin and other blood-thinning medications may cause bleeding. In fact, the overwhelming majority of patients who have microscopic hematuria do not have cancer. Irritation when urinating, urgency, frequency and a constant need to urinate may be symptoms a bladder cancer patient initially experiences. Oftentimes, though, these are merely symptoms of a urinary tract infection and antibiotics become the first line of treatment. (Bladder Cancer Advocacy Network - BCAN, 2016e)

However only about 1 in 1,000 cases of gross or microscopic hematuria are associated with Bladder Cancer many other conditions can cause it. (American Bladder Cancer Society, 2016a)

By highlighting the other possible conditions to which bladder cancer symptoms can be attributed, these examples suggest that concern over detecting the disease may be exaggerated and potentially unwarranted. Mobilized here, these more common conditions serve as a red herring insofar as they distract from the possibility of bladder cancer and require unnecessary treatments prior to consideration of cancer as the cause.

Finally, bladder cancer is rendered a particularly nefarious and sneaky threat due to its ability to infect with few symptoms and/or no sense of dis-ease on the part of patients. As such, feelings of wellbeing—indeed another type of masquerade adopted by the disease—obscure ill health and undergird the duplicitous and dangerous threat of bladder cancer (i.e., a threatening disease that can slip by with little to no materialized symptoms). For example, the following excerpts emphasize the lack of disconcerting sensations surrounding symptoms:

People assume they will feel symptoms from cancer, but almost four years later I still feel no symptoms at all. (Bladder Cancer Advocacy Network - BCAN, 2016f)

When I took my sample back it looked okay to me but there was blood in it when the doctor checked it. I then had an ultrasound, x-ray and cystoscopy. I was not concerned by this as I felt fine. (Bladder Cancer Advocacy Network - BCAN, 2016b)

Not finding cancer on this test [urine cytology] doesn't always mean you are cancer free. (American Cancer Society, 2016d)

Similar to the threats posed by the disease masquerading as other issues or being rationalized away by other conditions, these examples highlight how the lack of pain and discomfort—as well as the lack of definitive proof about the absence of cancer—make the disease that much more difficult to identify and understand. Lacking the signifiers traditionally associated with serious health concerns, bladder cancer ultimately deceives with a false sense of security and health. As such, the disease is presented here as



ambiguous because it fails to align with the expectations of ill health and disease.

**Mystique.** The mystifying nature of bladder cancer is alluded to in representations of the medical establishment and its *modus operandi* for dealing with the disease insofar as the disease is a challenge for physicians. As such, bladder cancer's mystique is mobilized by requiring a high degree of specialization and/or expertise in the treating physician, or preferably teams of physicians to try to penetrate the mystery using their collective skills.

Despite an overall reliance on medical experts and opinion, these discourses highlight the mystique of bladder cancer by calling into question the authority and ability of nonspecialist individual physicians to handle such an ominous disease. As these are common discussions about physicians in these discourses, this construction of physicians presents them as lacking the credibility that they are stereotypically imbued with in the medical community, especially when it comes to expertise with a mystifying disease like bladder cancer. For example, the following excerpts construct regular physicians as naturally unqualified to deal with bladder cancer, and thus specialists must be sought out by patients:

Many urologists don't know enough about bladder cancer. If you want the best treatment, find a highly-regarded urologist who specializes in bladder cancer. If you can, seek help in a major cancer center where they treat many cases of this disease. Choose a urologist you trust and with whom you feel comfortable. Find a doctor who will talk to you. (Bladder Cancer Advocacy Network - BCAN, 2016d)

It is important that any type of cystectomy be done by a surgeon with experience in treating bladder cancer. (American Cancer Society, 2016a)

Blood in the urine is not something that can be ignored and should be checked by a urologist who understands bladder cancer and can give you the best care. (Bladder Cancer Advocacy Network - BCAN, 2016f)

Unlike the official discourses about breast cancer, these discourses consider qualified

physicians to be the exception and under/unqualified physicians to be the rule. This construction of the medical community at large portrays it as fundamentally uninformed about the disease. As such, the specter of bladder cancer is rendered more sinister and mysterious by a medical establishment mostly incapable of understanding it or providing effective care. Furthermore, this shift in the representation of the medical establishment also places the onus of responsibility on patients to find the “right” physician, thus requiring the patient to adopt the role of expert until an official replacement can be located, thus further enhancing the daunting nature of the disease.

Happening concurrently with the characterization of regular physicians—that is, drawn against the skills and training of elite specialists—as inherently under/unqualified to handle the mystique of bladder cancer is the representation of them as potentially incompetent, as well. Similar to the imperative placed on patients to find experts in the treatment of bladder cancer, this construction of physicians relies on the (common) threat of—and need to avoid—misdiagnoses to further underscore the inadequacy of modern medicine’s approach to dealing with bladder cancer. This theme is demonstrated in the following excerpts about misdiagnoses and second opinions:

Before my diagnosis, following a bout with kidney stones, my local urologist had diagnosed me with chronic urinary tract infections. In April, 2008, after voiding a huge amount of blood, I called my doctor’s office and a nurse told me that there was nothing to worry about because it always looks like there is more blood than there actually is, but, I could make another appointment if I wanted. (Bladder Cancer Advocacy Network - BCAN, 2016a)

Get 2nd, 3rd and 4th opinions if you are so inclined. Doctors can and do vary significantly on the treatments they recommend. (Bladder Cancer Advocacy Network - BCAN, 2016c)

It is highly recommended to always get a second opinion from a major center that deals with a high volume of bladder cancer. Studies have shown that the experience of the Urological Surgeon, Oncologist and Pathologists can make a

difference in outcomes. (American Bladder Cancer Society, 2016d)

In keeping with the understanding that the disease is mysterious and often ineffable, regular physicians are portrayed as generally not knowledgeable about how to detect or treat bladder cancer, and thus these excerpts construct the opinions of these nonelite physicians as frequently ineffective, and even potentially flawed and deleterious (hence, the normalized nature of receiving multiple opinions on treatment options). As such, the complexity and mystery of the disease occur alongside the threats of medical ineptitude such that they all reinforce the representation of bladder cancer as a unique and severe threat.

Aligning with the understanding that bladder cancer is largely invisible in—and unknown by—the medical establishment, and thus necessitates specialists to treat, is the notion that the preferable way to combat the disease is via a *team* of medical practitioners. Unlike official discourses about breast cancer—which frequently hinge on the importance of family and the integration of other support systems to maintain a woman’s commitment and responsibilities to her loved ones—these discourses about bladder cancer position a team of healthcare providers at the center of the disease (and, incidentally, relegate social and emotional support systems mostly to the margins). The importance of a medical team, as opposed to a single urologist, underscores the complexity and inscrutability of the disease insofar as multiple minds are needed to approach it. For example, the following excerpts highlight not only the complexity of a team’s composition, but also the impact of a team as a support system:

Depending on your options, you can have different types of doctors on your treatment team. [...] You might have many other specialists on your treatment team as well, including physician assistants (PAs), nurse practitioners (NPs), nurses, psychologists, social workers, nutrition specialists, rehabilitation

specialists, and other health professionals. (American Cancer Society, 2016a)

Your cancer care team will be your first source of information and support, but there are other resources for help when you need it. Hospital- or clinic-based support services are an important part of your care. These might include nursing or social work services, financial aid, nutritional advice, rehab, or spiritual help. (American Cancer Society, 2016a)

However, the truth is that the time to have a discussion about your sexuality with your treatment team is when you are making treatment decisions. (American Bladder Cancer Society, 2016a)

As these examples suggest, a bladder cancer diagnosis is a complex enterprise ideally requiring specialists to handle the disease, though teams thereof are preferable.

Importantly, this emphasis on the centrality of providers operates not only to keep it within the medical realm (as opposed to the psychosocial realm), but to reinforce the magnitude of the disease, as well. By emphasizing the varied specialists in a medical team and the integral nature of this team to the success of one's treatment, these excerpts underscore the complexity of the disease and position it as particularly sinister such that it necessitates the combined experiences and expertise of these practitioners. Therefore, the inadequate ways in which modern medicine approaches bladder cancer underscores the mystique of the disease and renders it more cunning and sinister since it necessitates an army to address it.

**Patient agency.** Undergirding the overarching motif of ambiguity in these discourses is the valorization of patient agency via an articulation of the patient as a seeker of a bladder cancer diagnosis. The importance of patients feeling imbued with a sense of control over their health is highlighted by an emphasis on overseeing and monitoring the ambiguity of the disease: both the deceptive physical symptoms and the well-meaning but severely limited medical practitioners (including teams, but especially

individual physicians). This emphasis on agency as information seeking—rather than resource identifying—thus reinforces the notion that the disease is largely unknown to the medical community and, in some cases, possibly even beyond the comprehension of patients. Patient agency, then, is mobilized in these discourses as the ability to navigate one’s way through the ambiguity of bladder cancer through data gathering (and specifically gathering the “right” data), and mobilizing that information rationally in decision making processes.

Information seeking, as mobilized here, valorizes individual efforts to research the disease and learn details that are specific and relevant to one’s situation and diagnosis. For example, the following excerpts address the importance of patients taking the initiative to research the disease and conferring with loved ones and healthcare providers about confusing information:

When faced with a diagnosis of bladder cancer, you and those that care about you are thrown into a frightening place where knowledge is potentially lifesaving. (American Bladder Cancer Society, 2016c)

Bladder cancer is a treatable disease. Learn as much about your diagnosis as you can. Look on the internet, search medical libraries, request BCAN’s patient handbook. Read the literature yourself. If you find that researching it upsets you, let someone close to you do it and bring you the relevant information. (Bladder Cancer Advocacy Network - BCAN, 2016c)

The support from my family and friends has helped me in ways I could never explain or be able to repay. However, my need for knowledge could not come from them. While researching on the internet, I will always be grateful that I stumbled across BCAN. (Bladder Cancer Advocacy Network - BCAN, 2016f)

As these examples demonstrate, patient agency—when located within the realm of information and research—is positioned as an integral part to a patient’s survival and one’s overall journey with cancer. In these cases, data gathering tends to supplant other actions or even an emphasis on moving forward. That is, researching the disease is the

primary action available to patients and as such must be prioritized, particularly since the ambiguity of the disease enhances the challenge of knowing how to deal with it.

Significantly, in contrast to these positive representations of patient agency are those articulations of distress that result from such action, thus emphasizing how the ambiguity of the disease positions patients as needing *both* to learn about the disease *and* how to navigate their way out of the distress that results from this knowledge. This Catch-22 of securing information and then needing to secure comfort and reassurance regarding that information emphasizes the mystique of the disease insofar as learning about it ultimately disturbs and disrupts patients. Implied in these discourses is an expectation that patients should moderate their information seeking insofar as they should not become overwhelmed or tempted to stray from expert opinion. In these cases, the potential downsides to patients ostensibly taking control of their diagnosis through research are used here to support a limited definition of patient agency that hinges on patient irrationality. That is, the perceived emotional distress of learning about bladder cancer is presented as the rationale for limiting patient agency and privileging certain types of information over others. For example, the following excerpts articulate the reasons why limiting patient knowledge can be preferable:

And to add even more complexity to this emotional storm is the fact that you have to learn enough about your diagnosis to make informed decisions. While knowledge is power it needs to be the right information that fits your situation and is reliable. (American Bladder Cancer Society, 2016f)

Doing blanket research before you understand your personal diagnosis may not only leave you with information overload but could cause unneeded worry. Start with the basics and once you have your exact diagnosis use that to give direction to your research. (American Bladder Cancer Society, 2016f)

As these excerpts suggest, part of the patient's responsibilities is to know how much

information to learn before it becomes a burden. Again referencing the upsetting nature of researching bladder cancer, these examples construct information seeking—and patient agency as the force behind it—as potentially deleterious to the health of patients. Because these discourses delimit patient agency by tethering it to threats of emotional distress and the imperative of finding the “right” information, they result in a double bind that requires patients to research enough to be proactive, yet not enough to become overburdened. This balance—though certainly ideal in theory—is particularly challenging in light of the previous directive that knowledge can be lifesaving. By putting patients in this bind, these discourses articulate individual agentic action as aimless, thus further drawing patient agency against the mystique that surrounds bladder cancer in the United States. These articulations of patient agency underscore the mysterious and disturbing nature of the disease, and thus concede that agency is an illusion since little can be done about it.

### **Common Discourses**

Relative to other cancers—for example, breast and skin—little consistent news coverage appears about bladder cancer. This dearth of coverage, consistent with the disease’s reputation as the “invisible cancer,” underscores the idea of the disease being largely unknown both to the medical community and the general population. The fragmented discourses about bladder cancer in the popular press reflect how the disease is conceived of in the U.S. public imaginary (however limited that might be). Articles in mainstream news—specifically those in *The New York Times*, *USA Today* and *USA Today Magazine*, *Los Angeles Time*, *Wall Street Journal*, *Huffington Post*, *Rolling Stone*, *Chicago Tribune*, *The Washington Post*, *Reuters*, and *Boston Globe*—serve as the funnel

through which ideas about the disease are mobilized and circulated. Whereas official discourses about bladder cancer highlight how the disease is unknown and unknowable to all involved parties—patients and providers alike—common discourses about it both extend and depart from this notion to posit the disease as entirely unintelligible, without shape or character. Accordingly, in the absence of a malevolent and vaguely agentic disease, the common discourses seek culpability across two alternate parties: the medical establishment/pharmaceutical industry and the patient.

### **Unintelligibility**

Cohering with and elaborating on the “official” understanding that bladder cancer is inherently unknowable, common discourses about it render the disease as so ambiguous that it is entirely unintelligible. Perhaps because of this increased degree of ambiguity, the disease is rendered as totally amorphous and nebulous, with no character attributes like duplicity or mystique. The ambiguity of bladder cancer is frequently mobilized through discussion about the various symptoms or health issues that confound accurate diagnoses of the disease. Due to its similarity to other conditions—symptomatically speaking—the disease is largely unintelligible to both patients and the medical community because it lacks signifiers that distinguish it from other health issues, or make it easy to identify and understand, and thus this lends a masquerading mystique to bladder cancer. The nebulousness that shrouds the disease in mystery is articulated as both common and unexpected (i.e., the symptoms are common, but dealing with the disease and the ramifications of a misdiagnosis are unexpected). An example of the former is featured in *Huffington Post*:

Symptoms of bladder cancer include chronic urinary tract infections (which you



can now get an on-line UTI diagnosis and prescription to treat without a doctor) or bladder inflammation, blood in the urine, difficulty or pain when urinating or unexplained swelling in the lower extremities. (Collins, 2015)

As this article indicates, the common nature of bladder cancer symptoms—so ordinary, in some cases, that they do not require doctor’s appointments to diagnose—position the disease as unusual relative to the other standard health issues that could be responsible for these symptoms. Relatedly, as hallmarks of other health concerns, these symptoms are often invoked in discussion about misdirection and misdiagnosis, issues that bespeak the unknown and ambiguous nature of bladder cancer due to their prevalence and severe consequences. Thus, the ambiguity of bladder cancer is apparent in these discourses at both the symptomatic and diagnostic stages. For example, the following excerpts highlight the masquerading nature of the disease:

Quivers had no idea she was sick until 10 days earlier, when she had rushed to the doctor with an alarming symptom: She suddenly found herself unable to urinate. The problem, she learned, was a cancerous mass pressing on her bladder. During the surgery, doctors were initially pessimistic as they discovered how far the cancer had spread. (Hiatt, 2013)

My mother's end, nearly 20 years later, was because of bladder cancer, misdiagnosed for more than a year as a urinary infection. When the pain was too much, and the correct diagnosis finally made, it was too late. She was gone in less than four months. Proper testing combined with an accurate diagnosis might have saved her. (Dupont, 2014)

“In many cases, there are significant delays in diagnosing bladder cancer, especially in women,” Hardie said. Doctors and patients alike tend to dismiss the symptoms, thinking they're dealing with postmenopausal bleeding or a common urinary tract infection. “I was treated for urinary tract infections for a year” before anyone suspected cancer, she said. (Peres, 2016a)

As these examples indicate, the ambiguity of the disease often centers on misdiagnosis, resulting in physicians failing to recognize the disease. Whereas the article from *Rolling Stone* emphasizes how the disease can lurk and remain dormant before triggering serious

health complications, the *Boston Globe* and *Chicago Tribune* articles underscore the confounding implications of the disease which direct attention to other—more common—health issues (e.g., urinary tract infections). As such, the disease is constructed as beyond comprehension for both those experiencing it and those trying to detect and treat it.

Unintelligibility is also mobilized through emphases on both the lack of knowledge about the disease and the lack of innovation in treatments for it. Despite its prevalence and severity, the disease is constructed here as one that lacks definitive and consistent answers in the medical establishment, thus underscoring the notion that little is understood about the disease beyond its prevalence and severity. The following excerpts bespeak both this contradictory nature and dearth of answers:

Q: I have T1 bladder cancer and am being treated with BCG [Bacillus Calmette-Guerin] immunotherapy. I dye my hair dark brown every four weeks, as I have been for 20 years. I heard that hair dye is linked to bladder cancer. Should I stop using color?

A: Your question is surprisingly difficult to answer. For decades, epidemiologists have been debating whether hair dye increases the risk of cancer. The problem is that studies often are contradictory. (Graedon, 2016)

“It is well known that bladder cancer tumors have certain molecular alterations, but the problem is that there has been little data regarding which patients should get additional therapy, especially if there is no radiologic or pathologic evidence that the cancer has spread beyond the bladder,” explains Lotan of Texas' Simmons Cancer Center. (Lotan, 2014)

If hyperthermia is shown to help treat bladder cancer, “it's another option, and with the range of chemotherapy and novel agents it may be a much better option,” Dr. Kelly said. “Taken together, the studies tell us that hyperthermia is effective in bladder cancer, and further work will help establish which patients benefit most.” (Wang, 2015)

Attending to both the causes of and treatments for bladder cancer, these examples suggest that the entire trajectory of a patient's journey with the disease is liminal and marked by

ambiguity. Exacerbating this struggle is the long term inscrutability of the disease, which bars clarity from emerging despite critical distance, the passing of time, and severity of condition. With little evidence or knowledge to guide or inform one's cancer battle, then, the medical establishment—and by extension patients—are presented here as figuratively having their hands tied when trying to understand and handle the disease.

Similarly, the general lack of medical research and innovation is highlighted in discussion about the (few) new treatments being explored. In these cases, minimal research—and uncertain subsequent approval and distribution of treatments—perpetuate the unknown nature of the disease by emphasizing its status as an ignored disease. For example, the following excerpts emphasize the rarity of innovation regarding bladder cancer:

And just last month, data from Roche's advanced bladder cancer study lit up the international medical community, pointing toward what could be the first major breakthrough in over 30 years for this dangerous cancer. (Smith, 2014)

Roche's Genentech unit, which developed the drug, atezolizumab, said it plans to discuss the results with health authorities in an effort to bring it to market as soon as possible. If approved by regulators, it could become the first of a new wave of cancer immunotherapies to be cleared to treat bladder cancer, and the first new treatment for the disease in the U.S. since 1998. (Loftus, 2015b)

A new class of drugs that retrain the body's immune system to attack cancer cells is bringing hope to people with bladder cancer, a disease for which no new medications have been developed in three decades. (Peres, 2016b)

Whereas the previous section articulated the disease as shrouded in ambiguity and uncertainty, these excerpts underscore the unintelligibility of the disease by constructing it as a puzzle that has long lacked solutions, thus resulting in a dire decades-long dearth of innovation. Highlighting the impact of innovation on the medical community and patients at large, these excerpts suggest that both groups are equally befuddled by this

enigmatic disease. In this context, then, those dealing with the disease are positioned as blindly dealing with a disease that defies form or definition.

### **Corruption**

In the wake of ambiguity about the disease and in light of the high threat it poses, these common discourses move the disease beyond mysterious to unintelligible, and as such it is divested of character. Accordingly (and perhaps inevitably), other targets move into the sightline, with the obvious one being the medical establishment/pharmaceutical industry. Naturally aligning with the lack of knowledge and innovation on the part of the medical establishment is an underlying notion that corruption undergirds the detection and treatment of the disease in the United States. In the absence of information about the disease, then, the medical establishment and pharmaceutical industry become suspect through the perception of perpetuating and exploiting the unknown and unknowable nature of bladder cancer by conning patients, ignoring the disease, and/or abandoning research that fails to turn a profit. The limited attention paid to this disease by the medical establishment—per these discourses—largely hinges on the befuddling nature of the disease (as discussed above) and the ways in which medical practices can turn a profit based on the general lack of knowledge about it. For example, articles in *The Wall Street Journal* highlight the ways in which patients have been exploited by physician choices regarding treatment:

The results suggest that robotic surgery may be no safer than open surgery, despite being more expensive, Dr. Bochner said. A 2010 study in the *Journal of Urology* found robotic bladder removal procedures cost an average of \$16,250, or 11.2% more than the average cost of \$14,610 for open surgery. (Walker, 2014)

The pricey bladder-cancer test, known as FISH [fluorescent in situ hybridization], has been part of that program. Urologists at 21st Century Oncology ordered it frequently, says Richard D. Fernandez, its senior pathologist from 2009 until late

2010. “There was in the background, I suppose, a financial component” to the urologists' propensity to order the test, he says. (Carreyrou & Adamy, 2014) In a letter to a friend, the manager of a Florida urology practice worried in 2010 that her company would attract federal scrutiny for its frequent use of an expensive bladder-cancer test. The manager's concern involved a program at 21st Century Oncology Holdings Inc.—a national chain of cancer practices—that gives its urologists a financial incentive to order the test from a central in-house lab. A federal law since the 1990s has prohibited “self-referral,” in which doctors can profit from Medicare-reimbursed procedures they order. But 21st Century Oncology and many physician groups around the country have found ways to do it anyway, exploiting an exception to the law in ways its writers didn't anticipate. (Carreyrou & Adamy, 2014)

As these excerpts suggest, physicians routinely utilize both unnecessary surgeries and tests to suit their financial interests, rather than provide quality care to patients (or even match standard operating procedure regarding diagnosis and treatment, in these cases). Whereas, as described above, lack of physician knowledge contributes significantly to the ambiguity of the disease, these excerpts position their ignorance differently, as disingenuous, nefarious, and avaricious. Patients, then, face a double-bind of dealing with either uninformed or greedy physicians, neither of which is prepared to provide optimal care (nor willing to, in the latter case). Thus, these discourses posit that the corruption that plagues the medical establishment hinges on physicians skirting both the law and the knowledge boundaries of patients who do not know to demand some surgeries over others.

Similarly, the lack of treatment development—as elaborated on in the previous section—is rearticulated here via discussion of the stalled production of drug treatments (including the limited selection currently available). Hinging on financial considerations—that is, drug development failing to be financially solvent and/or promising—the corruption of the pharmaceutical industry is constructed here as depriving patients of needed and adequate treatment options. For example, the following

excerpts highlight the role (or lack thereof) of financial incentive in studying the disease and developing treatments:

BCG, a liquid delivered into a patient's bladder, is expensive to manufacture because it is derived from live bacteria. Yet because the therapy is 25 years old and no longer protected by patent, it fetches only about \$145 a vial, compared with about \$2,700 for a vial of Avastin, a newer, patented drug for other forms of cancer that hasn't had shortage issues. BCG's low price, coupled with the complexity and cost of manufacturing, has made the drug unattractive for many companies to produce, says Erin Fox, director of the drug information service at the University of Utah. [...] "This totally took me by surprise," she [a patient] says. "It was the very first time I had to think about the drug companies as failing the people that they're supposed to be there for." (Loftus, 2015a)

Although bladder cancer is the fifth most common malignancy in the U.S., it comes in 11th in terms of research funding, according to the Bladder Cancer Advocacy Network. "For many years, bladder cancer was ignored," said Dr. Gary Steinberg, director of urologic oncology at University of Chicago Medicine. "The pharmaceutical industry was not interested." (Peres, 2016a)

In a small study, Roche's drug, known as MPDL3280A, shrank tumors in 43 percent of a subset of patients with advanced bladder cancer. The company might now make bladder cancer the priority for its first approval rather than lung cancer, Daniel O'Day, head of Roche's pharmaceutical business, said in an interview here. [...] Companies are exploring whether a PD-L1 test can be used to determine which patients should get the drugs. That would be important because the drugs are expected to cost at least \$100,000 a year. (Pollack, 2014a)

In these cases, the pharmaceutical industry is similarly aligned with the medical establishment insofar as decisions regarding patient care are profit-driven. In keeping with the invisible nature of bladder cancer, these discourses underscore the understanding that the disease is mostly unknown, and thus the dearth of research is presented here as naturally resting on financial considerations (as opposed to the severity and prevalence of the disease). Patients, then, are positioned as needing to adapt to the financial interests and questionable development decisions of the pharmaceutical industry.

## Patient Morality

Imbricated with the unintelligibility of bladder cancer and concern about the corruption that seemingly stalls medical innovation is an emphasis on patient morality, and thus patients are targeted and held responsible for their disease. Centering patient accountability as the norm, these discourses mobilize blame to articulate not only the poor choices that exacerbated one's propensity for bladder cancer, but also to identify the proper way to be a bladder cancer patient (i.e., one who takes responsibility for one's diagnosis). The following excerpts—perhaps not surprisingly—center on smoking as both a primary cause of bladder cancer, but also a habit frequently espoused by bladder cancer patients, and thus highlight how patients must be held accountable for their diagnoses:

More than half of bladder cancers in the U.S. are the result of smoking, and 90 percent of smokers with the disease are aware of the connection, according to a new study. [...] “Bladder cancer patients smoking at diagnosis appear to accept that their own smoking caused their cancer, positioning them for a more motivated (and more likely successful) attempt at quitting,” Bassett said. (Doyle, 2014)

Survivors of lung or bladder cancer, which are often caused by cigarette smoking, were the most likely to still be smokers. (Salahi, 2014)

Emphasizing that cancer patients are knowledgeable about the causal link between smoking and bladder cancer, these discourses position the locus of responsibility entirely within the patients. In these cases, patients are expected not only to take responsibility for their diagnosis, but also make amends for it, as well (i.e., by attempting to quit). Since these discourses cannot lock into particular behaviors and actions due to the unintelligibility of bladder cancer, they articulate equally universally “bad” habits at the center of the quagmire of disease. This results in commensurability between the vastness

and generic nature of bladder cancer and smoking.

Also occurring within this construction of patient morality is an emphasis on the retroactive and proactive steps patients could and should take. In keeping with the above emphasis on what patients knew/know about their diagnoses, these discourses highlight what patients did/can do about their diagnoses. For example, the following excerpts detail the ways in which cancer patients are interrogated and prompted to perform accountability:

I remember my mom saying that one of the many difficulties in her time living with cancer was having people try to figure out what she could have done differently. You know, to prevent a giant tumor from growing in her bladder and eventually crushing her organs. “Did you drink too much?” “Did you stand near a microwave?” “Did you not eat solely organic vegetables grown in a garden no further than 10 miles from your home?” She felt like she was constantly defending her life choices (which, might I add, included going to bed at 8:30 p.m. most nights, running seven miles every morning, and only drinking a glass or two of wine on the weekends). (Leyko, 2015)

Phelps' brushes with cancer now have him coaching up in a different way. He is trying to alert men about the importance of getting annual physicals that include prostate and bladder screenings. When Phelps turned 60, he made a point of going regularly to his doctor. Now he goes twice a year, and he thinks it might have saved his life. “If I went for a physical last October and something kicks in November, and I wait until next October to see the doctor again, I could have had some serious issues here,” Phelps said. “Men need to stop being macho. Make yourself a priority and get yourself checked.”(Sherman, 2013)

By emphasizing the expectation for patients to be fully accountable for their cancer diagnoses (both in the midst of cancer and during recovery), these excerpts highlight how the disease exists in popular discourses primarily within the realm of individual responsibility and morality. That is, patients are interrogated for what they have done wrong (e.g., eating nonorganic foods) and implored not to make more errors in the future (e.g., wait too long to get a physical), thus suggesting a commensurability between ambiguous disease and vague, general, and diffuse actions or failures. This privileging of



individual agentic efforts, while empowering in theory, is imbued with both blame and shame, and calls into question both the decision-making capabilities of patients and the righteousness of their diagnosis (i.e., whether it was “deserved” or not). Inherent to this representation of patients is the common practice of blaming the patient (Gulyn & Youssef, 2010). New to this practice, however, is the idea that the prescribed actions are as diffuse, vague, and ambiguous as the disease itself. Relatedly, while the perceived corruption on the part of the medical establishment/pharmaceutical industry—the other half of the two-sided coin of blame—may or may not be actually occurring in practice, scholars have noted that whenever patients are held responsible/blamed for their own condition, attention is deflected away from the role of structural and institutional factors and agents relevant to a given health condition (Crawford, 1980).

### **Summary**

Inquiry into the rhetorical construction of bladder cancer confirms but also gives a bit of shape to the overall invisibility of the disease on the U.S. public agenda. In discourses disseminated by health organization websites and mainstream news coverage, the disease is represented as mostly unknown and unknowable, though this is mobilized in different ways. Official discourse characterizes the disease as ambiguous insofar as it is duplicitous and mysterious, while common discourse articulates it as completely unintelligible. While these characterizations may seem interchangeable, they feature distinct differences: the official discourse lends some shape to bladder cancer, whereas the disease is incomprehensible in the common discourse, defying any delineation—even ambiguous. These differences in disease characterization have distinctive implications for actors in the respective narratives. Furthermore, in the former discourse, advocating for

medical teams underscores the ambiguity of bladder cancer, and patients are drawn as seekers of information about the disease. In the latter discourse, the absence of form, shape, or definition of the disease, the medical establishment/pharmaceutical industry and patient, respectively, are rendered suspect. This suggests a casting about for agency, a rhetorical move that aligns with the ideology of individualism that permeates the U.S. healthcare system's approach to health and disease management (Crawford, 1980). By attempting to identify, locate, and/or remove responsibility for the disease, these discourses suggest that comprehension of the disease potentially resides in the articulation of action and accountability (i.e., what can be done about the disease and who is positioned to partake in these actions). Conspicuously absent from this levying of responsibility for bladder cancer are the structural/institutional agents that are traditionally associated and tasked with public health. This notable departure operates as a form of denial, suggesting that authoritative bodies take their cues from—rather than instruct—other definable agents (in this case, patients).

## CHAPTER IV

### SUSPICIOUS MINDS, SHAMED BODIES: MORALITIES AND RESPONSIBILITIES IN SKIN CANCER DISCOURSE

As one of the most common cancer types, and one of the most obvious, skin cancer is uniquely situated as figuratively and literally visible in the U.S. public imaginary (Jensen et al., 2014). This figurative visibility manifests in a variety of official initiatives to raise awareness about the disease and news coverage about both the disease and related issues (e.g., tanning bed legislation) such that the disease parallels breast cancer awareness and is the inverse of bladder cancer's invisible nature, despite melanoma rates being commensurate with bladder cancer rates (National Cancer Institute, n.d.-a). Tensions inherent to the disease—for example, the disease is comprised of both banal types that occur with such great frequency that they are not counted by cancer registries (i.e., basal cell and squamous cell carcinomas) *and* one of the most deadly forms of cancer that can strike anywhere on or in the body (i.e., melanoma)—render it an important site of inquiry to examine how medical organizations and news coverage, as official and common discourses, respectively, rhetorically construct the disease and ways for handling its prevalence and severity (Skin Cancer Statistics, 2015).

In this chapter, then, I analyze how a selection of national health campaigns and mainstream news coverage rhetorically construct the disease and articulate the processes

involved with its detection, prevention, and treatment. Specifically, this dual approach attends to how the ideas circulated in public health and awareness campaigns are potentially taken up, mobilized, and negotiated in popular news discourse in order to illuminate if, where, and how these ideas featured in official and common sources converge and/or diverge. Exploring the potential differences and similarities between how prominent voices in public discourses about skin cancer construct the disease has implications for patient care, public understanding about the disease, and the construction of future campaigns.

### **Official Discourses**

Generally constructed to inform the public about—and potentially ameliorate the effects of—a worrying health condition or issue, public health campaigns instruct consumers in the processes of detection, prevention, and treatment. This centering of not just knowledge acquisition, but also behavior change—that is, what patients can *do* about the health condition/issue—is a particularly interesting area for rhetorical inquiry. How patients are constructed and instructed to change inevitably reflects, reinforces, challenges, and/or creates cultural perspectives about the disease, those affected by it, and the causes of and treatments for it. As such, official discourses about skin cancer have the potential to shape public understanding about the disease and those involved with it, including the medical establishment, regulatory agencies, and patients.

Similar to the multitude of initiatives employed to raise awareness about breast cancer, skin cancer is at the center of a variety of government and health organization campaigns. Those selected here for critical interrogation were included because of their unique perspectives on different aspects of the disease. First, the Melanoma Research

Foundation features two self-detection awareness programs—#GetNaked (#GN) and Check Me Out! (CMO!)—that instruct consumers in the proper procedures for examining their own bodies for skin abnormalities. Second, The Skin Cancer Foundation advocates for the benefits and processes of abstaining from sun exposure for aesthetic purposes (e.g., tanning) via the Go With Your Own Glow (GWYOG) campaign. Finally, The National Council on Skin Cancer Prevention instructs in sun-safety measures, especially for families partaking in outdoor activities, via their annual Don't Fry Day (DFD) program (which—not coincidentally—coincides with Memorial Day).

These campaigns and programs warrant study due to their authorial status, credibility, prevalence, and longevity. Reflecting a variety of perspectives on how to manage the disease, these discourses represent the official dictums for how to be sun safe and proactive in detection, resulting in a sample of programs endorsed by governmental agencies (e.g., Don't Fry Day) and constructed by leading skin cancer authorities (e.g., #GetNaked). When analyzed together, these discourses portray the disease as one that is the specific responsibility of each individual patient insofar as patients are identified as appropriate diagnosticians of the condition, as well as held accountable for the use of preventative measures, or lack thereof. The “privatized” nature of managing the disease is further demonstrated in the ways in which patient responsibility is mobilized, mainly as matters of morality and authenticity.

### **Privatized Skin Cancer**

These campaigns construct skin cancer and processes for dealing with it through the valorization of patient agency in classically neoliberal fashion such that managing the disease is “privatized” and firmly situated in the sphere of patient responsibility and

accountability. By placing patients at the center of the skin cancer conundrum, these official discourses articulate individual agentic action as preferable—even superior—to medical intervention. Therefore, physicians and the medical establishment are positioned as resources, if relevant at all.

**Patient as expert.** Central to the construction of skin cancer as privatized is the assumption that patients—rather than physicians—are superior detectors of abnormalities and experts on the body. Whereas doctors know skin cancer *generally*, patients know their own skin *specifically*, and thus are configured here as the authorities on what constitutes a threat to their optimal health. Since deviation from the norm is the crux of this threat, patients are presented as responsible for creating and understanding their own norm, distinct from that which may be dictated by any authority on skin cancer, as demonstrated by the following excerpts:

#GetNaked and check your skin for new or changing spots. You know what your “normal” is. (Melanoma Research Foundation, 2017a)

Pay attention to your skin and know what is normal for YOU. Bring any mole or lesion that is new or changing to the attention of your dermatologist right away. (Understand Melanoma, 2014)

Most melanomas are spotted by patients so **know your skin well**. [original bold] (Melanoma Research Foundation, 2013a)

As these examples suggest, patients must obviously be the experts on their own bodies due to the variation of what constitutes “normal.” Because the imperative to know one’s own “normal” can be a life-or-death situation, the imperative to know one’s self—rather than specific medical advice—is of utmost importance. Related to this presumption of patient expertise is the labor that is expected to go into achieving this level of self-knowledge. Establishing the norm against which any deviation is measured necessitates

extensive labor on the part of patients, and the routinized tasks required to monitor and maintain this norm are naturalized and rendered necessarily distinct from medical involvement or intervention, thus further undergirding the notion of patients as superior to the medical establishment. For example, the following excerpts emphasize the expectation for regular monitoring of the body:

Since you are more likely than your doctor to notice a funny-looking spot or a change in your skin, **#GetNaked** and make monthly skin checks part of your routine. [original bold] (Melanoma Research Foundation, 2017c)

Research shows that patients, not doctors, are most likely to spot melanoma. The Melanoma Research Foundation encourages you to thoroughly check your skin each month for moles that are new, changing or different than other spots on your body. (Melanoma Research Foundation, 2013b)

The best way to detect skin cancer early is to examine your skin regularly and recognize changes in moles and skin growths. (National Council on Skin Cancer Prevention, 2016a)

By highlighting the individual effort that must be taken by patients to identify threats to the body, these excerpts reaffirm the superiority of patient expertise over physician knowledge, as well as suggest that patients must be continuously suspicious of their bodies and any changes that potentially occur. The labor necessitated by knowing one's own skin confers a sense of medical authority on patients such that they employ expertise in deciding if, when, and why physicians must be contacted.

Also occurring within this construction of patient superiority is the articulation of physicians as supplementary—rather than primary—to skin care and monitoring. By privileging the individual agentic efforts required and expected of patients, these campaigns position the medical establishment as secondary to the patient's first line of defense against skin cancer and thus expect patients to shoulder the responsibility for skin cancer care via both detection and prevention, with only minimal assistance from

physicians. For example, the following excerpts allude to medical intervention insofar as it occurs only after patients have labored over their health and utilized their expertise to determine the presence of abnormalities:

Increase your chances of catching melanoma early by carefully examining your skin once a month and visiting a dermatologist once a year. (Melanoma Research Foundation, 2017b)

Routinely examine your whole body for changes in your skin and report concerns to a parent or healthcare provider. (National Council on Skin Cancer Prevention, 2016b)

#GetNaked is the MRF's early detection campaign designed to raise awareness about melanoma and the importance of being proactive—instead of reactive—about your health. (Melanoma Research Foundation, 2013b)

#Dermatologists agree sun protection is best method of preventing premature aging, #skincancer <http://ow.ly/102Br0> #DontFryDay. (National Council on Skin Cancer Prevention, 2016)

Whereas several of the previous examples have largely obscured the role of the medical establishment in the processes of skin cancer detection, these excerpts identify physicians as being necessary only when deemed appropriate by patients, thus reinforcing the notion that patients have the proficiency to both identify causes for concern and the ideal time to request provider assistance. As such, these campaigns indicate that the medical establishment—though necessary in isolated moments in a patient's life—is generally supplemental to patient expertise. In this way, patient action and prevention are the only viable solutions to the threat of skin cancer, and thus patients are presented as being in control of their lives and health while simultaneously selecting moments for supplemental physician intervention. That is, by explicitly referring to and implicitly referencing the physician-approval granted to preventative measures, these excerpts suggest physicians are often absent from the process of detecting and preventing skin



cancer and primarily supplemental in nature.

### **Virtues of Patient Responsibility**

In keeping with the construction of skin cancer as privatized and positioned in the personal sphere, patient responsibility for the prevention and detection of skin cancer is rhetorically mobilized in these discourses as matters of morality and authenticity. That is, partaking in/failing to adhere to sun safe practices are constructed as issues central to one's character and demonstration of genuine concern for self and others. As such, the threats posed by skin cancer extend beyond one's health to include one's character.

**A matter of morality.** The articulation of personal responsibility as a moral issue tethers one's character to one's decision-making processes regarding sun-safety measures. This attention to acting in an ethical manner centers largely on the actions taken in regard to caring for children, thus further adding to the responsibility imbued in the individual actions of consumers. For example, the following excerpts from the Don't Fry Day campaign emphasize the ethical imperatives in both maintaining proper sun safety measures and applying/modeling those same measures to and for one's offspring:

In the same way we teach kids to wear bike helmets, we can also teach them to wear wide-brimmed hats. (Melanoma Research Foundation, 2016)

You wouldn't let your child do this [a picture of a child smoking]...so why would you let them do this. [a picture of a sunburned child in a swimming pool] (Don't Fry Day, 2016a)

1 in 5 children will grow up to get skin cancer. Don't let your child be the ONE. [original caps] (Don't Fry Day, 2016b)

As these excerpts suggest, the failure of parents to exercise good judgment about sun safety is tantamount to negligence at best and abuse at worst. By equating good parenting and setting a good example with practicing sun safety, these excerpts imbricate moral

responsibility with skin cancer prevention such that being a good person means being a good steward of one's skin and subsequently instilling the same sun-safe values in the next generation.

Relatedly, the practices of skin cancer detection and prevention are rhetorically mobilized here as an obligation that people must take responsibility for out of love for the self and others. Similar to the notion of sun damage hiding one's true beauty and health, the following excerpts elaborate on this idea to conclude that unsafe sun habits are a form of self-abuse and negligence as a loved one. For example, the following excerpts highlight the importance of sun safe practices for the self and others:

As many patients and survivors have recounted, their melanoma was found by a friend or partner who happened to notice something different – and urged them to see a dermatologist. (Understand Melanoma, 2014)

Catching melanoma early could save a life. Be an MVP. Check out the ones you love. (Cure Melanoma, 2011)

Friends don't let friends get skin cancer. Don't tan. Don't burn. This May 27, #DontFryDay <http://ow.ly/102Br0>. (National Council on Skin Cancer Prevention, 2016c)

Whereas previous attention has been paid to the moral imperative of sun safety, these discourses articulate the relational imperative of maintaining one's health such that protecting the skin protects one's life and loved ones. Alluding again to the idea of unsafe sun habits equating with abuse, these excerpts undergird the notion that a person must engage in active prevention *and* detection so as to maintain health and the well-being of friends and family.

Another articulation of morality similarly invokes the importance of scrupulous decision making such that safe sun and tanning habits are presented as the *mea culpa* for past reckless behaviors. Emphasizing the importance of not only seeing the errors of

one's ways, but also modifying harmful behaviors, these discourses tether personal responsibility to educated decision making. For example, the Go With Your Own Glow campaign highlights the importance of managing one's past mistakes:

"I didn't think it could happen to me," she said. "I had read about skin cancer. I heard about the risks of tanning in sunbeds, but I thought it was sort of a myth." Luckily, the melanoma had not spread, and today, Donnar uses sunscreen, wears protective clothes, and avoids UV tanning. (Skin Cancer Foundation, 2016d)

Karissa Martin, Miss Ohio 2008, was 14 when she had a precancerous mole removed – possibly the result of a serious sunburn on her scalp a decade before. Martin speaks regularly at schools about the dangers of the sun, and appears on behalf of the American Cancer Society at events throughout Ohio. (Skin Cancer Foundation, 2016b)

In these cases, the proverbial "seeing the light" is triggered by faulty judgment on the part of the cancer victim—either indoor tanning or unsafe sun habits—such that modifying behavior is positioned as a necessary reparation for these mistakes. By detailing the extent of compensating behaviors undertaken by the cancer victims, these excerpts feature of a conversion motif—reliant upon witnessing and testimony to convince the "unsaved" to convert—that mobilizes morality as an antidote to the potential for the cancer comeuppance brought on by poor decision making and thus further entrench morality in skin cancer discourse.

**A matter of authenticity.** Attendant to the threats to one's moral character is the construction of skin safe practices as being the mark of an authentic person, or one who is self-actualized and comfortable in one's own skin. With much emphasis placed on tanning and the social cachet culturally ascribed to tanned skin, these discourses construct vanity as a threat to authenticity and position vanity as a central cause of skin cancer. In this way, then, embracing one's natural—authentic—skin hue is a solution to unsafe skin habits and subsequently the threat of skin cancer. For example, the following excerpts

from self-avowedly antitanning campaigns, Go With Your Own Glow and Don't Fry Day, emphasize the link between covering one's skin and maintaining one's beauty:

When you're out in the sun be sure to protect your skin. Shade, sunscreen, and a cover-up can go a long way to helping your natural beauty shine through. (Skin Cancer Foundation, 2016c)

Let your inner glow, glow. Get out of the sun. Grab some shade. There's nothing sexier than healthy skin. (Skin Cancer Foundation, 2016c)

Burning and blistering your skin is like smoking packs of cigarettes or excessive boozing. It's negative and gnarly and self-destructive. *You must love yourself*, which includes loving your epidermis. [original italics] (Doonan, 2009)

The natural color of your skin is beautiful. Keep it that way #protectyourskin every day <http://ow.ly/102Br0> #dontfryday. (National Council on Skin Cancer Prevention, 2016c)

There is nothing pretty about #skincancer. #protectyourskin every day <http://ow.ly/102Br0> #dontfryday. (National Council on Skin Cancer Prevention, 2016c)

Love your skin: give it a good cover-up on #DontFryDay & every day. <http://ow.ly/102Br0> #protectyourskin. (National Council on Skin Cancer Prevention, 2016b)

By suggesting that unsafe sun habits not only endanger one's true self, but ultimately hide one's authentic self behind damaged and diseased skin, these discourses render tanning and other questionable practices as hindrances to being a genuine, confident person. In this way, tanned skin is rhetorically constructed as a mask that conceals and threatens one's subjectivity such that self-worth is—not surprisingly—tethered to aesthetics and appearance. Relatedly, the importance of one's authenticity as a person is underscored by the holistic—not just aesthetic—benefits that abstaining from tanning yields. That is, people who embrace their natural hue are constructed as inherently vibrant and freed from the shackles of vanity, and thus poised to lead authentic and healthy lives. For example, the Go With Your Own Glow campaign features the

following excerpts:

According to makeup artist Dick Page, who created the look at designer Michael Kors's show [that of pale runway models], the look "is less about bronze this time, more about energy." (Skin Cancer Foundation, 2016a)

Tanning as a life priority is over. (Skin Cancer Foundation, 2008)

Finally, to put it simply, what hurts your health hurts your looks. Smoking, pollution sleep deprivation, poor nutrition, unprotected sun exposure, and high stress all put your appearance at risk. They take a toll on the way you look and feel. So, take care of your health and spirit, every day, because healthy skin is a beautiful thing. (Skin Cancer Foundation, 2016d)

While the previous examples emphasized physical appearance, these excerpts suggest that skin safe practices are part of a holistic approach to healthy, successful, and authentic living. As the first excerpt indicates, a model's pale complexion is rendered vibrant by focusing more on (seemingly internal) energy and charisma rather than an artificial glow. Since energy is constructed here as diametrically opposed to a bronzed appearance, natural vibrancy is also understood as being hindered by tans, both fake and real. Similarly, prioritizing healthy life choices is constructed as a natural path to healthy skin in the latter two excerpts such that authenticity arises from preferable alternatives to tanning and overall actions understood to be healthful (e.g., not smoking). Therefore, authenticity not only comes from the decision not to tan, but also from the decision to engage in alternate self-honoring behaviors.

### **Common Discourses**

The proliferation of skin cancer information from authoritative voices—via official discourses like public health campaigns—is concurrent with popular discourses about the disease in mainstream news coverage. These popular discourses can be characterized as common insofar as, even as they might reflect official discourses, they

engage resonant cultural sensibilities that shape how audiences understand and respond to skin cancers. Popular press news articles about skin cancer—specifically those in *The New York Times*, *USA Today*, *Time*, *People*, *Health*, and *Men's Health*—align with and underscore the privatized sensibilities of individual responsibility apparent in the official discourses, albeit in slightly different ways. The prevalence of privatization is mobilized here via suspicion of regulatory bodies; consumer shaming; and vanity, deployed in paradoxical ways.

### **Suspicion of Regulatory Bodies**

In official discourses about skin cancer, patients and physicians are articulated as complementary agents, if patients are vested with greater authority. Seemingly uncontested by the medical establishment, this relationship relies on patients both to know their own bodies and recognize the necessary time to request medical intervention. Conversely, common discourses construct an adversarial relationship that is grounded in a suspicion of physicians specifically and regulatory bodies generally. Undergirded by emphases on conflicts of interest, overcharging, and overtreatment, this suspicion throws into doubt the need for medical intervention at all, and positions patients as being potential victims of the whims and devices of authorities.

Prevalent in these discourses is a general sense of distrust directed at those regulatory authorities that dictate how one should prevent and treat skin cancer: namely, the medical establishment and private industry. While the roles of these experts and authorities are mostly obscured regarding involvement with patients (and their journeys with skin cancer), they are frequently implicated as involved in financial gain (often at the patients' expense). The medical establishment—the central authority on skin cancer

prevention, detection, and treatment—is rendered suspect by frequent references to the questionable intentions and actions of physicians. That is, physicians are portrayed, first, as being particularly susceptible to mercurial changes in diagnostic and treatment procedures such that new technologies are adopted with little or no obvious advantages to patients; and second, as prioritizing profits over outcomes. Additionally, allusions to corporate corruption likewise challenge the veracity of claims about optimal sunscreen use such that one of the first lines of defense for patients—that is, sunscreen—is rendered suspect. For example, the following excerpts allude to the questionable behaviors of physicians:

For decades, dermatologists have used their eyes, along with a magnifier called a dermatoscope, to try to distinguish abnormal but benign lesions from potential melanoma in order to avoid unneeded biopsies. Some dermatologists argue that these low-tech tools are still the most useful and worry that their colleagues are falling for expensive, cool-looking gadgets that may simply offer extraneous, and perhaps incorrect, data. “This technology should still be considered to be in the developmental stage,” said Dr. Roberta Lucas [...]. “We are better off when the system supports doctors who are thorough and unhurried; who examine and listen carefully and who empower patients to practice good surveillance and sun protection.” (Singer, 2013)

“It helps me see what I cannot see with my eye,” Dr. Day said [regarding new technology for finding melanoma]. “I have great comfort that I am not missing a melanoma.” (Dr. Day has been a paid device investigator and speaker for Mela Sciences; she appears in promotional videos on the MelaFind Web site). (Singer, 2013)

And even within the same Boston-area market, the price of removing a common type of skin cancer can vary by hundreds of dollars depending on the hospital. (Ungar & O'Donnell, 2015)

While it [Mohs surgery, a new type of skin cancer treat] offers clear advantages in certain cases, it is more expensive than simply cutting or freezing off a lesion. [...] Use of the surgery has skyrocketed in the United States – over 400 percent in a little over a decade – to the point that last summer Medicare put it at the top of its “potentially misvalued” list of overused or overpriced procedures. Even the American Academy of Dermatology agrees that the surgery is sometimes used inappropriately. (Rosenthal, 2014)

As these excerpts suggest, the pricing for services rendered and the use of some technologies and procedures over others are largely depicted as unjustified by the medical community and even questioned by the federal government and other regulatory bodies. As such, physicians—although occasionally portrayed as victims of the system in ways similar to patients—are represented as advocating for (and participating in) collusion, often at the expense of optimal care for patients. This questioning of physicians' integrity tarnishes the benevolent reputation traditionally attributed to them and foment suspicion of the medical establishment in general. Relatedly, in addition to being portrayed as easily influenced by financial gain and technological advancements, the medical establishment is also tethered to Wall Street in these discourses such that scientific innovation is imbricated with profit margins:

But the treatments will not be inexpensive. Merck said Thursday that the drug, known generically as pembrolizumab, would cost about \$12,500 a month, or about \$150,000 a year. [...] Some Wall Street analysts have said that collectively cancer immunotherapy drugs could achieve annual sales of tens of billions of dollars. (Pollack, 2014b)

Investors and Wall Street analysts began poring over the abstracts late on Wednesday, looking for information that could affect the stocks of pharmaceutical companies. (Pollack, 2015)

Together, the drugs slowed or temporarily stopped tumor progression in 60 percent of patients, versus 11 percent of those who received only Yervoy, in a pivotal study of 140 previously untreated patients with melanoma, the deadliest type of skin cancer. But with a wholesale price of \$141,000 to \$256,000, even insured patients may not be able to afford their portion of the bill. Bristol-Myers shares rose 86 cents to close at \$60.03. (Associated Press, 2015)

The consistent inclusion of stock and pharmaceutical prices in discussions about cancer treatment advancements suggests that the medical establishment is in tune with the financial needs and considerations of investors rather than patients. With profits seemingly taking primacy over patient outcomes, these discourses position the medical



establishment and scientific innovation as being susceptible to and governed by the demands of shareholders.

Skin cancer prevention is also an arena in which corruption and self-interest on the part of medicine and science are intimated. These excerpts suggest that financial gain is usually central to awareness-raising and information dissemination such that examples to the contrary must be noted:

Take endorsements and seals of approval with a grain of salt. The Skin Cancer Foundation gives a “seal of recommendation” to sunscreens, but only if their manufacturer has donated \$10,000 to become a member of the organization. (Rabin, 2013)

The sunscreen study was paid for by the National Health and Medical Research Council of Australia. No sunscreen makers contributed. (Kolata, 2013)

Dr. Wang, who is a spokesman for the Skin Cancer Foundation, which gets funding from sunscreen manufacturers, tells his patients to apply sunscreen as if they were adding a second coat of paint to a house. (Saint Louis, 2014)

These characterizations cast further doubt on those authorities that dictate how best to avoid sun damage (and subsequently cancer). As alluded to here, the relationship between expert advice and directives for sun safety is articulated as grounded in financial considerations, resulting in a representation of authority figures as willfully participating in corporate corruption and deliberately hoodwinking consumers and patients.

### **Consumer Shaming**

In both official and common discourses about skin cancer, patient character is located as the impetus for responsibility, although in the former, character is tethered to morality, and in the latter, character is relative to intelligence and common sense. Significantly, these discourses diverge in their construction of at-fault parties: official sources note the bad choices of other—mostly abstract—people, whereas common

sources more directly characterize the reader/audience as suspect: they anticipate irresponsibility on the part of the audience. This distinction also appears to be related to a conceptualization of the audience as *consumers* in the common discourses, as opposed to *patients* in the official discourses. Consumers, then, are the targets of shaming for their decisions and skepticism about their intelligence (a fate not shared by the patient articulated in these discourses). Additionally, official discourses intimate collusion between authorities and the patient, but the common constructs a contentious relationship between experts and the audience that is based in suspicion (as noted above) and vexation (i.e., authorities assume patients are going to make poor decisions).

By representing consumers as necessarily at fault for their potential or actual diagnoses, these discourses center understanding about the disease within the (flawed) actions of people and suggest that they must take actions to redress the harmful behaviors that led to their skin damage or cancer diagnoses. The motif of consumer shaming, then, hinges largely on the relationship between poor decision-making and individual responsibility. The first articulation of shaming discussed here is mobilized through an emphasis on consumer ignorance or defiance of sunscreen directions, thus positioning consumers as lacking the necessary intelligence and/or rationality to be sun safe. For example, the following excerpts identify the lack of knowledge as the central issue in skin cancer prevention via sunscreen and other related precautions:

By law, sunscreens can no longer claim to be sweatproof or waterproof – the truth is, you do sweat them off. And don't rush the spritz process. Yes, it's supposed to be quick, but you still need to be thorough. (Whitmore, 2014)

Wear your sunscreen, seek the shade, wear protective clothing and never, ever go to a tanning salon. Despite decades of repetition, many of us fail to follow that skin-saving advice – and a new study shows that's true even for people who have had the most serious form of skin cancer. (Painter, 2013a)

Will the new labels help consumers better protect their skin from damage? They will, skin health experts say – if consumers take the time to read the fine print and then choose and use the products wisely. (Painter, 2013b)

Some experts blame inappropriate use of sunscreen, saying that people do not apply enough lotion (a golfball-size dollop) or do not reapply it every two hours as instructed. [...] It's not clear that sunscreens with higher SPFs actually are more effective, and consumers may not apply them as frequently. (Rabin, 2013)

The main reason to reapply a broad-spectrum sunscreen every two hours isn't that it breaks down; most of today's sunscreens are stable in sunlight. Rather, reapplication is crucial because most people don't apply enough sunscreen in the first place. (Saint Louis, 2014)

As these examples suggest, consumers (and patients, to a lesser extent)—even those trying to be sun safe—fail to follow or attend to instructions for the proper application of sunscreen and other safety measures, and as such authoritative bodies are positioned as having to (re)educate and/or account for the poor decisions of the masses. In this way, consumers are held accountable for every iteration of unsafe sun behaviors—for example, failing to apply sunscreen correctly, requiring frequent reapplication of sunscreen because of initial failure, and reading/following directions—that lead to sun damage, and thus they are positioned as both the problem and the solution, responsible for the damage but also expected to make material changes in their lives to prevent skin cancer (a marginally optimistic outlook that does not feature elsewhere in these discourses).

Consumers are similarly shamed for potentially not exhibiting common sense, a sentiment that here seems equated with compliance with those known behaviors that experts encourage—and often assume—from patients and consumers. The failure to follow directions or partake in sun-safe measures is utilized here as a foundation to assume that consumers have ostensibly learned their lesson and are ready/able to act in ways consonant with expert recommendations for tanning and sun safety. The following

examples apprehend consumers as cognizant of their past failures and/or as ready to make amends for them:

If you have used tanning beds in the past (you're not doing it anymore, right?), experts advise that you tell your dermatologist to include that information in your skin cancer history. (Gwinn & Mazziotta, 2015)

**You won't read "wear broad-spectrum spf 30 daily!"** here, because by now, you know you should. [original bold] (Whitmore, 2014)

"Sun protection is a total package" and includes shade, broad-brimmed hats and "common sense," says Henry Lim, chief of dermatology at Henry Ford Hospital in Detroit. (Painter, 2013b)

"Too many people think that sunscreen is just to protect them from a sunburn," says Brooke Jackson, MD. "They wear it at the beach but not every day." Truth is, your skin is vulnerable all year round. (Gwinn & Mazziotta, 2015)

By highlighting language that assumes consumer knowledge of (and even compliance with) proper sun and tanning safety measures, these discourses take on a paternalistic view of people insofar as they must be cajoled into behaving correctly, or verbally reprimanded if compliance is not attained. Unlike the previous examples—which assume an incompetent consumer/patient—these excerpts apprehend a consumer who can take direction but still ultimately comes up short, and ultimately needs guidance and prompting from authoritative figures.

Paired with this emphasis on consumer failure is an expectation for individual agentic action to prevent and/or combat the dangers of sun exposure and skin cancer. This mobilization of shaming, while contradictory with the initial portrayal of consumers (and some patients) as incompetent, is rendered coherent in light of these discourse's emphasis on paternalism. That is, because some people are considered malleable and able to take direction, these discourses position consumers as able to take action as long as these actions are within the boundaries outlined by (suspect) experts:

The report does not tell us all to live in caves. “Enjoy the great outdoors,” Lushniak says, “but take steps to protect your skin.” (Painter, 2014)

People who diligently use sunscreen every day can slow or even prevent for a time the development of wrinkles and sagging skin, a new study found. (Kolata, 2013)

If you get color, you are going to damage your skin on some level. In the old days, sometimes they’d ask me [actor Hugh Jackman] to get tan for a role, but now I spray-tan if I need it. (People, 2015)

Ask your partner to examine the skin on your back. “I don’t recommend checking more frequently than monthly, because you’re less likely to notice changes when you look at something every day,” Dr. Perlis says. [...] Take photos of moles, spots, or patches, and then compare them to what you see next month. (Fowler, 2014)

Because we look at our skin in the mirror every day, we are the first line of defense against this disease. [...] So it’s crucial to regularly look at your own skin, and to speak up if you spot something suspicious on someone else’s. (Gwinn & Mazziotta, 2015)

Not limited to just proper sunscreen application measures but also inclusive of self-examinations, early detection, and prevention of skin damage, these discourses indicate that individual agency and actions—while possible—are delimited by expert opinion, though curiously absent of any authoritative oversight. This absence—though somewhat amended via pleas to report any suspicious abnormalities to dermatologists—further undergirds the privatized nature of skin cancer insofar as consumers are expected to act simultaneously within the guidelines established by authorities, yet mostly outside of the control and assistance of these regulatory bodies. In addition to this, said bodies are not flatteringly depicted in this discourse in any case, resulting in a portrayal of apathetic and controlling authorities.

Similarly, these discourses address those messages that may dissuade people from taking adequate safety precautions or that may suggest these precautions are unnecessary.

Seemingly in anticipation of consumers—yet again—failing to act appropriately and—yet again—needing supervision and direction, the following excerpts clarify studies that, respectively, suggest that skin protection is primarily necessary earlier in life, and that skin cancer is often the result of genetic chance rather than poor safety habits (two findings that could, arguably, confuse a person into thinking sun safe measures are not needed):

“This doesn’t mean that you’re off the hook if you’re careful early in life,” Dr. Qureshi added, since too much sun exposure at any age is linked to an increased risk of other forms of skin cancer. (O’Connor, 2014)

The element of chance does not, however, mean you should stop wearing sunscreen or take up smoking. “My biggest fear is that people will do nothing. The opposite is true,” says Tomasetti, who stresses that while we may not be able to prevent all tumors, we can focus on early detection and taking advantage of lifesaving treatments like chemotherapy and radiation, among other things. “We need to do everything we did before, but we want to do it even more than before.” (Park, 2015)

As these excerpts suggest—and align with previous articulations of the consumer—authorities turn a wary eye to consumers such that poor decision-making is assumed to be their default mode. Whereas consumers are occasionally assumed to be agentic in their health decisions in these discourses generally, these examples specifically underscore the general misgivings about the population’s competence as a whole. As such, concerns about noncompliance with recommended behaviors situate consumers as being continually in need of prodding to make good decisions.

### **Double-Edged Vanity**

References to vanity and its association with skin appearance and modification permeate official and common discourses, with both emphasizing how vain behaviors—for example, indoor/outdoor tanning and scant clothing worn in the summer—cause skin

cancer. Abstention from these behaviors, however, takes different tacks in these discourses such that official dictums encourage the abandonment of this type of vanity so as not to hinder one's authentic self (including natural skin hue), while common voices suggest that bolstering people's sense of vanity will enhance compliance with sun safe behaviors. In this way, the common constructs vanity as a *pharmakon*, both the cause of skin cancer and the most compelling impetus for skin cancer prevention. The former articulation of vanity centers on the reasons for unsafe sun/tanning measures such that skin cancer victims are understood as wanting to maintain a certain lifestyle or aesthetic, particularly those visual signifiers associated with being outdoors and living an active life (e.g., have a tanned appearance from vacationing and/or outdoor activities). For example,

I used to think if I didn't come back with a little bit of color, it's not a real holiday. (People, 2015)

But she adds that she has interviewed melanoma survivors who have let down their guard. "Survivors have told me that it is very important for them to maintain a normal outdoor lifestyle." You can do that but "be smart about it," says Ali Hendi, a dermatologist in Chevy Chase, Md. (Painter, 2013a)

There's no way to square skin-cancer statistics in the United States – more than 3.5 million cases diagnosed yearly and almost 10,000 deaths – with the number of Americans showing off their tans. They aren't all getting body paint. They've been lectured about sunscreen and shade and hats. But vanity trumps sanity, and melanoma rides its coattails. (Bruni, 2014)

Some experts say combating the problem is a matter of raising awareness about the dangers of tanning. But many women said in interviews that they were aware of health risks but cared more about how they looked now. (Tavernise, 2015)

Madison, 21, a student at the University of Rhode Island, said tanning made her feel "more confident and more comfortable when I walk around." "Sometimes it makes me feel thinner," she continued. "It has all these weird effects that just make me feel better about myself." (Tavernise, 2015)

In these cases, the emphasis on vanity as a danger to one's health results in a tension over authenticity and superficiality; changing or modifying one's natural self is portrayed as

highly problematic and evidence of insecurity, whereas accepting oneself is the optimal—and intelligent—choice. Moreover, embracing one's natural appearance is presented as the disposition and choice of an emotionally healthy person. Thus, partaking in “bad vanity,” or that which results in altering one's natural appearance, is challenged as both physically and emotionally unsound.

Concomitant with this articulation of vanity as a source of cancer is the mobilization of vanity as a potential solution, or at least a primary prevention tactic. Identifying the seemingly futile nature of appealing to the rational sensibilities of consumers, these discourses construct logical decision-making and pleas thereto as a strategy that must be made to reflect and align with the vain desires and choices of consumers. In this way, reasoning with the public is portrayed as a lost cause and thus vanity must be utilized in order to gain the attention of—and hopefully compliance from—the public. For example, the following excerpts highlight vanity as the common language, so to speak, shared by consumers and authorities:

“Maybe sheer vanity will encourage young people to be proactive and use their sunscreen, because the cancer fear doesn't seem to be getting through to them,” says Deborah Sarnoff, a dermatologist in New York City and a senior vice president at the Skin Cancer Foundation, a non-profit group that receives funding from sunscreen makers. (Painter, 2013c)

I'm heartened to see the idea that to be sexy and beautiful you have to be tan is gone. People like Nicole Kidman have done a great job. She was made fun of when she was a kid in Australia because she stayed in the shade. No one is making fun of her now. (People, 2015)

Much like the articulation of vanity as unreasonable suggests that consumers must be implicated as responsible for their fates, these excerpts suggest that consumers will ultimately be responsible for their health via attention to trends and appearance-saving sun habits. In this way, vanity is reframed as a temporal issue such that staving off sun



damage aids in a person remaining attractive longer than a person who is reckless about sun damage. Appealing to cultural notions of antiaging sentiments that permeate U.S. popular and lived culture, these discourses align with the idea that consumers (and subsequently patients) must be prodded into acting appropriately. Thus, consumers—much like patients—are constructed here as requiring oversight and coaxing to make optimal choices for their health.

In this discourse, sun-safe clothing represents an industry response to this deferral of vanity. Positioning this industry as that which will ultimately keep people out of harm's way (rather than superfluous and vain), these discourses identify the fear of aging as both an additional threat to and type of vanity, thus rationalizing the need for this interest in sun-safe clothing. Speaking specifically to the assumption that sun-safe outerwear is not attractive, the following examples rely on the presumption that appearance takes primacy over health, and therefore new developments in outerwear allow consumers to be both vain and healthy, as well as beat the aging effects from early life sun damage:

But there's a way to rationalize these prices [for rash guard surf-gear that doubles as sun protection]: just take into account how much a small tube of good sunscreen costs and multiply by the number of days between Memorial Day and Labor Day. (Zissu, 2013)

Say "sun-protective clothing," and the imagination drifts to outfits that look like hazmat suits, safari attire or possibly a burqa. But in the last few years, sun-shielding apparel has become more flattering and fashionable, reshaping the market and potentially improving public health. "For a long time, I felt there was a need for this," said Alexandra Kotur, the alabaster-skinned creative director at Town & Country [...] "I burn easily and had been dressing like a crazy person on the beach." [...] "There was just no clothing out there that was protective and pretty." While cancer is a concern of many of her customers, she said, vanity is what's really driving sales, particularly among women in their 20s and 30s. "Once they start to see signs of aging – the wrinkling and spots – they really want to cover up," Ms. Reilly said. (Murphy, 2013)

In addition to highlighting the temporality of sun safety, these excerpts appeal to the importance of acting sensibly in the face of guaranteed skin damage if spending prolonged time in the sun. By emphasizing both the ways in which sun-safe clothing compensate for other safety precautions (i.e., purchasing sunscreen) and the ways that sun-safe clothing have traditionally be constructed (i.e., as unattractive), these excerpts align vanity with commonsense decision-making such that consumers are positioned as unreasonable for *not* participating in these types of vanity. Furthermore, insecurity is only associated with early age vanity, suggesting that younger consumers are both targeted with sun safety discourses and appeals to the deferral of vanity. As such, consumerism—via vanity—is sanctioned as a necessary step in accomplishing one’s sun safety precautions and forestalling the negative effects of sun exposure, a rhetorical move that underscores both the temporal and competitive notions that reside at the intersection of health and vanity in skin cancer discourses. Finally, this general approach to consumers constitutes a “fight fire with fire” approach which mobilizes the very disdain that underwrites the general apprehension of consumers throughout these common discourses.

### **Summary**

Inquiry into the rhetorical construction of skin cancer in competing U.S. discourses is necessary for identifying fissures and intersections in how the disease is discussed, negotiated, and understood across contexts. These official and common discourses highlight tensions over the roles of the medical establishment and patient agency in the fight against the disease. Whereas public health campaigns emphasize the importance of individual agentic efforts in prevention and diagnostic procedures—often at the expense of the medical establishment’s expertise—common voices position

physicians as adversarial toward patients and their optimal health, thus undermining the medical establishment's credibility and integrity. Appealing to patient's individuality, official discourses apprehend patients as experts on their own bodies and construct the maintenance of the natural or authentic body as a moral imperative. Conversely, consumers are identified and shamed for their failings to practice sun safety amidst a surge of interest in sun-safe clothing. Significantly, common discourses about skin cancer are unique—relative to those about breast and bladder cancers—in their distinction between consumers and patients, with the former being held responsible for their skin damage and increased potential for cancer diagnoses and the latter granted clemency in the face of suffering at the hands of a corrupt medical establishment. In this way, patients are shielded from the shaming and indictments of foolishness and vanity that are levied at consumers.

## CHAPTER V

### PROGNOSIS: CONTRIBUTIONS AND IMPLICATIONS OF DISCURSIVE CANCER PRACTICES

Despite decades of awareness, research, and even a federal war against it, cancer is projected to be the leading cause of death in the United States by the year 2020 (if present conditions and trends remain stable) (Weir et al., 2016). This imminent increase in prevalence indicates the continued importance of attending to how cancer is covered and constructed in public health campaigns and mainstream news coverage, both official and common, especially since the latter frequently shapes public perceptions about the disease (Jensen et al., 2010, 2014) and the former educates populations about the disease (Campaigns, 2016). As such, rhetorical inquiry into respective discourses about these prevalent cancers is warranted to reveal how ideas about detection, prevention, and treatment circulate in the public imaginary. Attending to the nuances of these discourses is useful for potentially assisting health care providers in utilizing emergent understandings of optimal engagement, treatment, and care of cancer patients. In the preceding chapters, I attended to these discourses as relevant respectively to breast, bladder, and skin cancer to assess how official and common discourses in each case diverged and converged in meaningful ways. My analysis surfaced three primary rhetorical motifs that characterize not only cancer itself, but also patients and the medical establishment. I will first briefly summarize the findings for each respective cancer, and

then engage the emergent motifs that cut across all of them.

### **Breast Cancer**

In this chapter, I analyzed how public health campaigns funded by the Centers for Disease Control and the National Breast Cancer Foundation rhetorically constructed the disease and the respective roles of patients, physicians, and support teams in treatment processes, resulting in the centering of patients as responsible and accountable parties who are implicitly bolstered by the obscured medical establishment. In order to determine if/how these same ideas were drawn into common discourses circulating across the country, I analyzed 3 years' worth of mainstream news coverage, including *The New York Times*, *USA Today*, *Time*, and *People*. Contrasting with the official discourses about the disease, these articles centered the medical establishment as a harmful and corrupt apparatus that operates as a threat to the well-being and futures of patients.

### **Bladder Cancer**

In this chapter, I analyzed how online health resources about bladder cancer from the American Cancer Society, Bladder Cancer Advocacy Network, and American Bladder Cancer Society rhetorically constructed the disease as inherently unknown and unknowable such that both patients and individual physicians are rendered essentially powerless when faced with it. Additionally, I analyzed 3 years' worth of mainstream news coverage, including *The New York Times*, *USA Today* and *USA Today Magazine*, *Los Angeles Time*, *Wall Street Journal*, *Huffington Post*, *Rolling Stone*, *Chicago Tribune*, *The Washington Post*, and *Boston Globe*, in order to determine if and how these same ideas got taken up in nationwide discourses. In keeping with the general dearth of

discussion and apparent understanding about the disease, the common discourse suggests that the disease is not only unknown/unknowable, but rather is entirely unintelligible, without shape or character. Furthermore, the patient helpfulness identified in official discourses is carried over within this framework and is extended to characterize health providers as bumbling and dangerous, and unfit to address and deal with the disease.

### **Skin Cancer**

In this chapter, I analyzed how public health campaigns funded by the Melanoma Research Foundation, The Skin Cancer Foundation, and The National Council on Skin Cancer Prevention constructed the disease, patients, and methods of detection and prevention. Taken together, these official discourses portray the disease as a privatized and individual issue that must be dealt with at the directive of patient expertise and for the sake of maintaining the moral character of patients. Likewise, I analyzed 3 years' worth of mainstream news coverage—*The New York Times*, *USA Today*, *Time*, *People*, *Health*, and *Men's Health*—in order to ascertain how, if at all, these ideas about the disease and patient responsibility would be taken up in the common. Similar to official discourses, the common constructed the disease as privatized, but primarily mobilized in these discourses through an emphasis on consumer shaming and suspicion of regulatory bodies.

### **Rhetorical Motifs**

The discourse surrounding each respective cancer turned on particularized characterizations of the cancer at hand, patients, and the medical establishment, but it is instructive to note that clear rhetorical motifs emerged across them, as well. These motifs

articulate characterizations of cancer, patients as implicated parties, and the medical establishment's role therein.

### **Cancer Characterizations**

Despite the multitude of ways in which both official and common discourses discuss cancer, two primary characterizations permeate these discourses and provide the lenses for understanding the disease as either malevolent or ambiguous.

**Malevolent.** Drawing on the natural fear that cancer instills, these discourses frequently articulate cancer's malevolent qualities such that the disease is not treated as a static entity, but rather an active agent which operates outside the realm of intelligibility for patients and providers alike. This mobilization of agency on the part of cancer tends to take the form of deception and confusion, thus underscoring the threatening nature of a disease which, in these cases, defies logic and expectation. For example, the duplicitous nature of cancer is born from its ability to masquerade as other maladies or be dismissed because of its similarity to other health issues. Hiding behind the symptoms of common processes (e.g., menopause or menstruation) or health issues (e.g., bladder infections), cancer not only deceives, but also misdirects and propels both physicians and patients on fruitless quests for answers. This confusion, then, reaffirms the malevolent nature of cancer by obfuscating inquiry into symptoms as potentially indicative of cancer, and thus resulting in the understanding that cancer manipulates medical knowledge and sabotages medical intervention. Finally, the threat posed by cancer is sometimes understood through religious language and allusions. For example, skin cancer is suggested as a substitution for a vengeful god insofar as those who smite it will be struck down by the punishments of melanoma, disfigurement, and damaged skin, and thus converts to the

ways of sun safety must make amends for their past transgressions.

**Ambiguous.** In these discourses, cancer is inherently ambiguous and hard to define, identify, and understand. It is framed as a threat to health due to its nebulous and diffuse nature despite decades of research and seemingly countless dollars, resulting in relatively little understanding about what causes it, what prevents it, and what best treats it. The futility of powerful, expensive, and persistent interventions renders cancer rhetorically as even more ambiguous and perhaps forever unknowable. The nebulous nature of the disease is commonly apprehended as uncertainty about what causes it. For example, recommendations and/or questioning about healthful eating and similarly banal habits are speculated as potential causes or solutions for cancer, thus suggesting that patient control over their bodies must be wielded to partake in preventative, if unsubstantiated, behaviors. Additionally, the genetic makeup of a cancer diagnosis underscores this ambiguity by highlighting how genetic predisposition for one cancer may result in another un/related cancer, or no cancer at all, while no predisposition or family history has the potential to convince people they are not susceptible to certain cancers (when, in fact, they very much are). As such, understanding about genetic mutations and predispositions is articulated in the discourse in such a way as to heighten the confusion about cancer rather than assuage it. Finally, cancer often fails to align with traditional notions of ill health and disease such that certain cancers can mimic common health phenomena and confound practitioners, resulting in an imperative for patients to attempt to parse their diagnoses in the face of medical uncertainty.



### **Patients as Autonomous/Responsible**

A central motif on which all of these discourses hinge is the understanding that patients are responsible—either in whole or in part—for their cancer diagnoses, and as such they must be treated as autonomous individuals in their quests to regain optimal health and moral character. This emphasis on patient responsibility and accountability—as noted below—is mobilized through functional and moral imperatives, both of which obscure the systemic and structural factors that likely impact a patient’s ability to take responsibility for and action regarding their diagnosis. These articulations of individual responsibility contribute to current understanding of how neoliberal sensibilities that privilege individual agency and responsibility are deployed in these discourses.

**Functionally/logistically.** As these discourses suggest, the task of learning about, understanding, and addressing cancer is always already the patient’s responsibility, and thus entreaties to engage in extensive research about the disease operate both to foreground the patient and background the medical establishment. This emphasis on the functional and logistical responsibilities of patients is frequently invoked in discussion about the need for patients to learn the *right* information about their disease, as well as the *right amount* of that information, with little to no direction on how to accomplish either feat. Expecting patients intuitively to know how much information is “enough” reinforces the notion that patients must naturally be left alone to learn about cancer because the individual nature of the disease is matched by the individual preferences of those dealing with it. A related double-bind exists for female patients who are expected to account for and manage their bodies due to their unruly nature and confounding capacities due to menstruation and menopause. The female body is “othered” in these

discourses such that it is rendered suspect and in need of active medical and self-surveillance. Because a woman's body is a site of struggle for meaning in a medical context, female patients are assigned the additional task of compensating for and making sense of this struggle on an individual level for the benefit of the system.

The individualized nature of cancer is further underscored in articulations of patient responsibility for diagnoses. As elaborated on below, patients are regularly held responsible for their cancer diagnoses, with emphases placed on poor decision making, ignorance, obstinacy, and/or apathy, all of which center the patient as accountable to medical experts, and more severely, responsible for their ill health. A somewhat contradictory articulation of the patient coexists with this understanding of the patient as responsible for her/his diagnosis, and that construction suggests that the patient is an expert on her/his own body, and thus they must instruct the medical establishment on what is normal, appropriate, and needed. Since patients understand and define what is normal, they are portrayed as superior to the medical establishment which must then operate at the behest of this expertise on the part of patients.

**Morally.** In keeping with the understanding that patients are autonomous agents in the fight against cancer, these discourses also construct a complex of moral imperatives that call into question a patient's moral character during all stages of the journey with cancer, including hypothesized actions that led to diagnosis, actions taken to prevent it, and actions taken to maintain one's health post-cancer. These imperatives construct the patient as not only responsible, but also inherently accountable to others such that preventing and treating cancer are done at the behest of—and for the sake of—others. For example, managing one's body and cancer diagnosis is portrayed as a moral

duty insofar as patients must take care of and monitor/scrutinize the body for changes and problems—as well as research, understand, and comply with the nuances of one’s diagnosis—so as to maintain one’s ability to care for others. This moral responsibility becomes particularly salient in regard to breast cancer patients who have families, and caregivers who fail to teach and model proper sun safety measures in front of children. By centering the family in the cancer journey—as well as highlighting the female imperative of putting others before the self—these discourses indicate that surviving is a responsibility one has to others, rather than a personal goal or victory. As such, being a moral person and patient means being accountable to the needs and habits of the family. Lastly, the responsibility assigned to and expected of patients is also mobilized as a reverential and religious duty. As discussed above, cancer is understood as a malevolent and vengeful disease, and thus patients are constructed as either the unwashed masses or converts, with the former partaking in careless behaviors (e.g., tanning) and the latter declaring a *mea culpa* for their recklessness. These religious undertones—firmly situated in ecclesiastical notions of right and wrong—position the patient as the recipient of righteous punishment for past wrongdoings, and thus naturally tasked with making amends (e.g., performing self-exams or wearing sunscreen).

### **Conflicted Role of Medical Establishment**

In conflict with the reputation of expertise and benevolence traditionally ascribed to medical practitioners is the construction of the medical establishment in these discourses. Despite fleeting acknowledgement of expertise and ability, the persistent representations of physicians and other authorities cast them as being of limited utility/effectiveness and shrouded by an aura of suspicion about their methods and

motives.

**Limited utility/effectiveness.** Aligning with and reinforcing the motif of patient autonomy/responsibility that is pervasive across discourses, the role of the medical establishment is largely understood to operate in the background, and thus serve primarily as a resource waiting for patients to seek out. The consistent centering of patient experiences and expertise marginalizes the medical establishment and questions the efficacy of the expertise and abilities embedded therein, resulting in the understanding that physicians serve as supplementary support rather than a first line of defense. Even more prominent than the construction of a silent and plastic medical establishment is the notion that it is rife with problems such that everything about it—including individual physicians, technologies, and standard operating procedures—puts patients at risk of harm. In this way, patients must not only contend with the threats of cancer, treatment, and side effects, but they must also gird themselves against the threats posed by incompetence, lack of knowledge and qualifications, and the tenets of bad medicine. Thus, the visibility of the medical establishment in these discourses serves to question it and its potential for effectively and efficiently treating cancer patients. For example, the complexity of cancer can render individual physicians powerless, and thus necessitate teams of experts to handle it (although this expertise often comes with its own threats of patient exploitation for the sake of monetary gain, as discussed below). Additionally, the treatments and diagnostic procedures proposed and utilized by the medical establishment are often represented as ineffective at best and barbaric at worst, resulting in the implication that—at least in some cases—patients would have been better off without any medical intervention whatsoever.

**Suspect.** Attendant to the portrayals of expert incompetence and ineffectiveness in these discourses is the underlying concern that regulatory bodies are corrupt, and thus require circumspection on the part of the patients. Often articulated as indictments of financial gain over patient outcomes, this motif primarily hinges on the understanding that physicians and health-based organizations operate at the behest of financial considerations or those with financial interests. For example, controversies around the necessity of tests for different cancer types and the motives behind awareness raising call into question those who stand to benefit from the funds raised in both cases. Similarly, the proposed ways for preventing cancer are also questioned for the potential vested interests that exist in health-based organizations. For example, the suggested use of sunscreen is questioned for its veracity in light of the fact that the suggestions are written and promoted by those who stand to benefit from rapid consumption and replacement of the product (i.e., sunscreen companies contribute funds to skin cancer foundations).

Related to the limited effectiveness of physicians is the notion that physicians tend to have a fundamental lack of knowledge about cancer, and thus they adopt a reactive approach for dealing with it that requires standardized ways of treating all patients. In addition to being swayed by profit margins, physicians are also understood to be inherently mercurial and susceptible to changes in treatments and diagnostic procedures, regardless of the usefulness of the changes to patients or the soundness of the scientific research behind these procedures. Finally, the medical establishment is cast as suspect through the ways in which it is perceived to exploit patients and prey upon their desperation for answers and solutions. Extensive attention is paid in these discourses to the ways in which physicians benefit (primarily financially, as noted above) from the lack

of understanding on the part of the patients. With little agency or technical expertise to question or challenge physician recommendations, patients are constructed as having a dearth of options and ultimately vulnerable to the suggestions of designated experts. As such, physicians are portrayed as requiring unnecessary tests and treatments in order to maximize profits and boost their own status among those utilizing emergent technologies, all at the literal and figurative expense of cancer patients.

### **Convergences and Divergences**

The above motifs that construct cancer, patients, and the medical establishment in distinct ways were apparent across cancers and across both official and common discourses. However, there were notable variations, per respective cancers, between these discourses. Regarding breast cancer, official discourses construct cancer as an ever-present risk for women, assume patients are in control and understand their moral imperatives to regain health, and portray the medical establishment as secondary and at the will of the patient. The common, however, assumes that breast cancer is puzzling and largely not understood by practitioners, situates patients as always already harmed by the practices and inefficiencies of physicians, and highlights the extensive modalities of bad medicine that permeate the medical establishment. Similarly, official discourses about bladder cancer construct cancer as deceitful, patients as expected to take (limited) action against the disease, and physicians as ultimately insufficient to deal with it; conversely, the common portrays cancer as unintelligible, patients as morally culpable for their diagnosis, and the medical establishment as inherently suspect. Finally, official discourses about skin cancer construct cancer as righteous comeuppance for bad behavior, patients as responsible for their diagnoses, and physicians as supplementary

assistants to patients; the common draws on similar ideas to position cancer as the result of poor decision making, patients as irresponsible, and the medical establishment as corrupt.

These convergences and divergences suggest that, broadly, cancer is represented as a challenge sourced by issues external to the medical establishment (e.g., the female body is more prone to breast cancer) in official discourses, whereas it is confusing at best and unintelligible at worst in common discourses. Patients, likewise, are centered as responsible for their diagnoses and overall health in official discourses, whereas they are assumed to be victims of external agents, at best, or their own poor decision making, at worst, in the common. Finally, official discourses frame the medical establishment as well intentioned and often helpful, whereas the common question providers' effectiveness at best and trustworthiness at worst. While people affected by cancer—either through diagnosis or the diagnoses of family/friends—are likely to consult both kinds of discourses in the process of learning about/dealing with treatment, prevention, and recovery, and thus it is warranted to discuss practical implications, it is also important to acknowledge that there may be competing and even conflicting understandings that patients and the populace at large are engaging.

### **Contributions**

Analysis of the rhetorical articulations of breast, bladder, and skin cancer across official and common discourses suggests two primary theoretical contributions. First, this study contributes to health communication literature to the extent that it adds to critical inquiries in health communication. Specifically, it parses established knowledge about (problematic) assumptions of patient responsibility and the role of structural and

establishment entities, particularly noting that individual responsibility is mobilized differently across cancers with significantly different implications. While extensive critical health communication literature has established the problematic individual responsibility model of health communication, no one has as yet unpacked what this means and how it is mobilized. The current study, however, does just that by assessing the ways in which responsibility is mobilized and identities are constructed in relation to cancer. Alternatingly tethering morality, authenticity, accountability, and culpability to the choices of patients, these competing discourses construct dramatically different imperatives for patients that are dependent upon cancer type. As such, the mobilization of individual responsibility—though consistently invoked across these discourses and cancers—fails to provide a consonant view of patients and instead places mercurial expectations on them. Likewise, it is similarly significant how the medical establishment is seen as oppositional or inept in regard to certain cancers, particularly as some cancers are more closely associated with private industry and profit-driven ventures, and/or medical interventions that prove to be advantageous for the medical establishment as opposed to the patient. This oppositional view of the medical establishment is contrary to the well-established narrative of the benevolent—and often heroic—provider that permeates popular discourses about health and medicine.

Relatedly, identities were apprehended in distinct ways across these discourses and cancers, particularly as they relate to fulfilling the aforementioned imperatives of responsibility and accountability. Illuminating on their own terms, these findings are also valuable in that they lend definition and nuance to extant literature that has established that health care is broadly framed in the United States as a matter of individual



responsibility (Crawford, 1980; Dutta, 2010; Lupton, 2015). Said responsibility, this study reveals, is not “one size fits all,” as the type of responsibility varied across the discourses under review. Moreover, individual responsibility—however articulated—is correlated in many cases with particular identity markers, as well. Gender, for example, was revealed to play a role as relevant to women’s particular moral obligations to others as well as higher demand for vigilance in regard to their (as articulated) relatively more suspect bodies. Age was found to intersect with gender such that the construction of younger people’s—and particularly younger women’s—role in avoiding cancer hinged on expectations of irresponsibility and even immaturity. A final example of identity being brought to the fore in these discourses was demonstrated in the configuration of education and/or media literacy as central to handling one’s cancer diagnoses. In many cases, patients were assumed to have achieved a level of education or media literacy that would enable them effectively and efficiently to seek out the appropriate information in the right amounts at the opportune times (all of which assume access, awareness, and knowledge, and which underscore the patient’s role in learning about cancer generally and their diagnosis specifically).

Second, the significant differences in official discourses and common discourses in each case confirm that mainstream news, if historically appropriately characterized as official discourse in the past, cannot be said to categorically occupy that status any longer (at least not by default). This is primarily so because mainstream news now seems to be reflective of and responsive to broader cultural imperatives and responsibilities that are not reflected in the same way as official discourses (i.e., those institutional and governmental discourses of power that, per Ono and Sloop (1995) shape history and

control/create public space). This reconceptualization of what constitutes the “official” is undergirded by cultural and technological shifts in media outlets and formats, and concomitant widespread adoption of practices of engagement on the part of publics with mainstream media outlets, all of which have resulted in a mediascape, inclusive of mainstream media, that is no longer consonant with official discourse as historically and conventionally imagined. Additionally, while it is perhaps not justifiable to codify mainstream media as a variant of vernacularity, it is justifiable—per recent scholarship furnished by both media scholars (e.g., Bruns, 2006, 2008) as well as critical rhetoricians (e.g., Howard, 2008)—to trouble or at least complicate and nuance that original binary. To that end, this project hypothesized and has borne out that there is a viable “third way,” or category, of “common” discourse: a classification original to Howard (2008), but one that, contrary to his argument at the time, I find significant, distinctive, and germane. This “middle ground” discourse provides an added dimension to our thinking about discursive (re)productions, articulations, circulations, and negotiations of meaning and power. Indeed, the fact that my analyses surfaced substantial and distinctive variances between official and these common discourses supports this claim. Redefining the common to include mainstream cultural discourses acknowledges that clear distinctions between media producers and consumers have been irreparably blurred, and that the elite role of producer once occupied by mainstream news has—in many ways—collapsed into media production more generally (a shift no doubt enabled by the rapid proliferation of digital media). While the democratizing function of digital and social media is not under examination here, the dynamic synergy between traditional media (e.g., *The New York Times*) and social media (e.g., Twitter) has resulted in an inevitable mirroring of content

between the two in digital spaces. That is, mainstream news stories are shared/liked/pinned/et cetera frequently in social media to the extent that sites like Twitter have made adjustments to their user interface in order to accommodate the addition of links, and news sites now inevitably include comments sections and tools to share stories seamlessly via multiple social media platforms. This synergy, then, challenges the notion that the common only resides in ostensibly secluded (and assumedly oppressed) communities, and instead suggests that vernacularity can exist in spaces where the fluidity of power is both apparent and possible, and inherently drawn against those discourses that establish the status quo and that are far more fixed than news sources or social media accounts (i.e., institutional/structural discourses).

### **Implications**

Even though health providers are likely to know (and toe) the “party line” (i.e., ideas featured within official discourses) about how the medical establishment and its personnel function within the milieu of cancer care, the disjunctures relevant to common discourses are poised to be instructive for them. In all likelihood, patients/those affected are going to consult both official and common discourses, however, so the following implications assume as much. Thus, identifying those ideas about cancer that gained traction in the public imaginary via common discourses indicated four suggestions for potentially improving patient-provider communication and the construction of future public health campaigns. These implications, if abstract in nature, draw on the prevalent emphasis placed on patients in these discourses in order to illuminate potential fissures in the current standards of cancer care, primarily the management of expectations, removal of moral imperatives, facilitation of trust, and an acknowledgment of the competing

constructions of physicians.

### **Management of Expectations**

As these collective discourses suggest, patient agency and information-seeking habits are central to fighting cancer and engaging with the medical establishment effectively and efficiently. However, these expectations are often constructed via double binds that constrain patients in accomplishing the very actions advocated. Therefore, patients could potentially be benefited by clear directives of physician expectations, as well as contextualization of those directives (e.g., bladder cancer patients are implored to learn about their disease, but that information is often rendered useless by lack of knowledge about the disease throughout the medical establishment). Clarifying what patients are expected to do and what those efforts are understood/expected to accomplish could potentially reduce uncertainty about the processes of pursuing and receiving cancer care for patients and administering it for physicians.

### **Removal of Moral Imperatives**

Prevalent across these discourses is an emphasis on patient (and consumer) morality and the ascribed moral pitfalls that are perceived or understood to generate cancer diagnoses (e.g., smoking, not wearing sunscreen, not eating organic foods, etc.). By centering blame on patients (and consumers, to a lesser extent), these discourses invoke notions of guilt over poor decisions (i.e., a patient did a bad thing), and often escalate into shaming patients (i.e., a patient is a bad person). Since guilt appeals without shame are more effective and less prone to resulting in boomerang effects (i.e., patients do the opposite of the intended actions in the message; Boudewyns, Turner, & Paquin,

2013), those constructing cancer care messages could potentially benefit from removing shame-based guilt appeals from campaigns and patient interactions in order to avoid boomerang and other negative reactions (e.g., anger). Additionally, providers might also consider attempting to inoculate patients against those messages that contain problematic information (e.g., misperceptions about cancer, and that which suggests patients can control their cancer and whether or not they get it), and debunk this information directly and explicitly (even preemptively).

### **Facilitation of Trust**

Whereas official organizations and health advocacy websites generally assume competence and honesty on the part of practitioners, dissent apparent in the common discourse about the rectitude of the medical establishment suggests that physicians could benefit from an emphasis on the facilitation of trust so as to assuage concerns about various forms of corruption (e.g., overtreatment, unnecessary testing, collusion, etc.). Because much of common discourse about cancer turns on extensive suspicion of regulatory bodies and authorities, analysis suggests that patients could potentially benefit from enhanced transparency about the procedures for determining necessary tests, associated costs, and vested interests in related technology in order to eliminate—at least in part—potential concerns about the character and intentions of providers.

### **Physicians as Partners**

Conspicuously absent across these collective discourses is the idea of medical practitioners as partners (which is perhaps not surprising in light of the aforementioned motifs that position physicians as primarily antagonistic towards patients). Often pushed

to the foreground as incompetent or relegated to the background as silent assistants working at the behest of patients, physicians fail to earn parity with each other or even their patients in these discourses insofar as they are positioned as only strong in numbers and/or inferior to patient expertise. As such, added emphasis on the symbiotic relationship between patients and providers could potentially enhance public health campaigns, especially those campaigns that are seeking to enhance patient efficacy and agency through knowledge acquisition and medical expertise.

### **Limitations and Future Directions**

This inquiry is limited by key constraints on scope and context, and indicates ways to attend to these limitations in future research. First, the narrow scope of these three cancers occludes discussion of other prevalent—and, in some cases, more prevalent—cancers (e.g., prostate and lung). These specific types of cancer under study here are also often demarcated by gender, indicating that messages about them will potentially feature patterns consistent with normative gender roles and expectations in the US (e.g., breast cancer campaigns focusing on a woman's role in the family), thus limiting those messages constructed for a broader array of patients. Second, the specific 3-year time frame (2013-2015) chosen for this project is far from comprehensive, nor does it account for time-sensitive coverage of scientific breakthroughs about these cancers that happened before and after 2015. Finally, the discourses analyzed here are comprised solely of mainstream domestic venues only, thus limiting other perspectives (e.g., patient-created discourses) and international discourses.

Taking these limitations—as well as the findings of this inquiry—into account, I suggest the following directions for future research. First, a comparative study of

rhetorical constructions of other particularized discourses of health, illness, and medicine is warranted in order to ascertain how other prevalent health issues are taken up in common discourse. Second, a comparative cultural study of rhetorical constructions of health, illness, and medicine would be valuable in order to illuminate key rhetorical motifs in official discourse, particularly as they may or may not be consonant with the progression from individual responsibility to shame and blame that is endemic to U.S. discourses. This type of study could potentially reveal how notions of individual responsibility are constructed and taken up in varying discourses, and pay particular attention to how they potentially transmogrify from official to common discourse. Third, a comparative historical study of coverage of these same cancers from approximately 30 years ago would provide a theoretical contribution to the study of cancer discourses. Such a study should interrogate the potential variances between official discourse and what I am identifying as a viable “common” discourse now in order to establish whether there has always been a difference between the two, or whether there was little difference between official discourse and mainstream news venues back in the day (thus suggesting that the official/vernacular binary was more sustainable and defensible then as opposed to now). Fourth, a study of vernacular discourses as originally conceptualized would be interesting in order to note how lay discourses articulate these cancers, particularly in regard to rhetorical motifs, identity, and related factors identified in the current study. Attending to how vernacular discourses do or do not vary from common discourses—and in which ways—would further clarify and refine emergent conceptualizations of discourse relevant to power in a contemporary context. Such a study would benefit from including social media coverage in order to grasp how audiences are discussing and

making sense of these cancers. Through the inclusion of tweets, Instagram posts, shared links, hashtags, and similar social media fare, a study could determine how those who likely lack any expertise on the subject of cancer are making sense of it and engaging with other users on the same subject (thus also providing a sense of community that is central to original theorizing about the vernacular). Finally, a praxis-oriented future direction would be to create and mobilize a health campaign and/or practice that consciously attends to and engages common discourse could illuminate optimal ways in which to construct awareness-raising initiatives and interventions about prevalent cancer types.



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